

Spring 2016

# BRITISH ASBESTOS NEWSLETTER



100th Issue Commemorative Edition



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## *The Cover*

The central image on the cover of this the 100th issue of the British Asbestos Newsletter was designed by artist Conrad Atkinson “one of the most thoroughly humanist artists of our time.” Now in his seventies, Professor Atkinson’s awareness of the asbestos hazard developed from an encounter in the 1970s with asbestos campaigner Mrs. Nancy Tait at a London exhibition of his work about Pneumoconiosis and Silicosis in mining communities in the north of England. Their meeting at the Serpentine gallery resulted in a piece entitled: *Asbestos: The Lungs of Capitalism* (1978); this work was purchased by the Tate Gallery in 2007. From the very beginning of his career, Professor Atkinson has challenged assumptions about the public role of art and favoured “direct engagement, rather than detachment, community participation, rather than isolation, and honest representation, rather than any tendency towards the picturesque...”

Explaining the concept for the cover image, the artist said:

“I wanted to find a different approach... an optimistic approach to an extremely serious subject. As the ‘Official Artist of the US campaign to ban landmines (Vietnam Veterans Trust)’ I had to find a way to draw attention to this horror, to reengage a community with ‘compassion fatigue’ who were mentally editing out images of limbless children used in several campaigns. With the same attitude I’ve tried to draw attention with this cover, to use different images to convey the problems of asbestos. It is astonishing that forty years after I first met Nancy Tait, asbestos continues to pose a serious threat to human life. While the use, production and sale of landmines was banned under the Ottawa Treaty (1999), global sales of asbestos remain unregulated.”

ISSN 1470-8108

Published by Jerome Consultants – London, May 2016.  
Design and Editing: David Allen and Laurie Kazan-Allen  
Printer: Justasec Print Services, London HA8 6LH, UK  
– Printed on ECF paper from sustainable forests.

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## *Preface*

Dr. Morris Greenberg MB FRCP FFOM  
HM Medical Inspector of Factories: 1967-1985

Since the late 19<sup>th</sup> century, Britain has been the test bed for the asbestos industry. The commercial exploitation of the “magic mineral” was pioneered at workshops and factories in Scotland and England even as industry propagandists developed strategies to embed their products in national life. Asbestos was indispensable, they said; with its unique physical and chemical properties, fireproofing, insulation and automotive products containing it were both modern and desirable. Civilization, as we knew it, required asbestos.

From 1906 onwards, it has oft been asserted that cases of asbestos-related disease were due to historic exposures that occurred before asbestos was known to be harmful. The Courts and the public have repeatedly been asked to believe that there was no firm evidence of disease before 1930 (some 50 years after the start-up of the industry), or even as late as 1960, in the face of evidence to the contrary from Britain (1898, 1906, 1912, 1924), France (1906), Italy (1908) and America (1918). The man on the workshop floor and his employers have repeatedly observed associations between malignant and non-malignant diseases and exposures to a number of occupational agents, including asbestos, and deemed them to be causal, long before scientific publications appeared to validate their findings.

Even as regulations to prevent asbestosis were promulgated in Britain in 1931, it was apparent that they would be inadequate; nevertheless, it took until 1969 before their revision was attempted. Tinkering with regulation continued for 30 years until finally it was accepted, by national bodies and by United Nations agencies, that the term safe working with asbestos was an oxymoron, and that controlled working was not reasonably practicable, making a total ban ineluctable.

Long before the internet became a viable tool for ordinary people, the British Asbestos Newsletter (BAN) provided a much-needed public space for discussions about issues that impacted on the lives of individuals suffering from asbestos-related diseases. As both an information source and a facilitator, BAN personnel cultivated channels of communication amongst those tasked with supporting and representing the injured, including victim support workers, health and safety campaigners, trade unionists, lawyers, engineers, doctors, scientists and politicians. The breadth of the newsletters’ coverage is reflected by the content of this issue’s chapters and the affiliations of the authors. The ad hoc coalition of like-minded individuals and groups which coalesced over asbestos has achieved many policy and legislative changes which have benefited sufferers; some of the victories and the processes used to effect them are discussed in the following pages.

A decade after publication of the newsletter began, the UK government finally banned the use of chrysotile asbestos, the amphiboles having been banned previously. As welcomed as the long-delayed prohibition was, British asbestos death rates continue to rise. The role of the newsletter in collating the injustices and hardships experienced by ex-workers who continue to succumb to associated malignant and non-malignant disease and are still forced to fight for compensation is, perhaps, more important now than ever. With the passage of time, many of the companies responsible for negligent exposures have long since ceased to operate, or have reconfigured in a manner that obstructs their pursuit for compensation; this is compounded if their insurance companies no longer exist or challenge the extent of the cover for which they are responsible. Now, there are the victims of the “third wave” to serve (e.g. workers in construction, demolition, maintenance and servicing) who have been and continue to be exposed to in situ asbestos.

In 1892, the future King Edward VII asked: “If preventable, why not prevented?” Those who come to the world of asbestos afresh today, when informed of how long asbestos has been recognised to be lethal, are astounded and ask: “If they knew about it in 1898, (30 years after the start-up of the industry), why are people still continuing to be exposed?” Many of the answers to this question can be found in the pages of the unique resource which is the British Asbestos Newsletter.

# THE BRITISH ASBESTOS NEWSLETTER – THE FIRST HUNDRED ISSUES

Laurie Kazan-Allen

From the first tentative articles in the very earliest issues of the Newsletter, our prime motivation has been to make publically available resources which would be of benefit to people suffering from asbestos-related diseases. When we began publication (1990), vested interests in the corporate world and government departments still dominated the national asbestos dialogue; information vital to those suffering from asbestos-related diseases remained locked away in company archives or dusty files retained by insurers, legal representatives and trade associations. Access to government records and pertinent documentation was often problematic and always time-consuming. Asbestos claims existing “outside the pathway from well-organized unions to specialist solicitors” often floundered due to the lack of legal expertise of High Street generalists [1]. Further disadvantaging the injured was the fact that members of the medical profession, more often than not, refrained from advising patients of the existence of possible claims. These factors combined to produce “a significant pool of uncompensated [asbestos] victims” in the UK.

During the early years of publication, research for newsletter articles was done the old-fashioned way: via phone calls, desk-based research and personal meetings. The world wide web, although it existed, remained the preserve of a handful of techies and the appearance of social media platforms such as Facebook, Twitter, MySpace and YouTube was still some years away. Before the internet revolution, however, there was Nancy Tait. As the archives of her organisations, first SPAID and then OEDA (see: page 38: Nancy Tait and the Pursuit of Justice), show, Nancy provided formidable support for



Nancy Tait

ordinary people placed in extraordinary circumstances. By 2007, Nancy had: “handled over 3,000 cases, providing not only tremendous support to the victims of asbestos and their families but gaining greater recognition of the hazards of asbestos.”

Nancy’s reputation preceded her and I am not ashamed to admit that for some while I steered clear of meeting her; I had, after all, been warned about this fearsome advocate, of “her messianic fervour” and tunnel vision. Nancy did not do small talk and did not suffer fools gladly as many “expert witnesses” whose paths crossed hers found out [2]. When we finally did meet, it was obvious that she was a truly remarkable person for all the reasons that William MacDougall cites and many more besides. I, like so many others, benefited from her knowledge, wisdom, efficiency and organisational skills. I did not realise until reading William’s contribution that I had also worked for her – it seems that somewhere along the line, I was SPAID’s Press Officer. The fact that I don’t remember having been so anointed is irrelevant; if Nancy said it was so, I am sure it was.

## Effecting Change to Britain’s Asbestos Landscape

My personal relationship with Nancy Tait underpinned our collaborations. The same holds true for interactions with others active in the UK campaign for asbestos justice; it was individuals rather than organisations that developed the trust and commonality of purpose to engage in the many battles fought over the years. Many of them have agreed to contribute to this issue of the newsletter. Others whose role I would also like to acknowledge include: Alan Dalton, Richard Jackson, John Todd, Ian McKechnie, Frank Maguire, David Gee, Nigel Bryson, Rory O’Neill, Hilda Palmer, Mick Holder, Tony Whitston, John Flanagan, Mick Clapham, Jason Addy, Mavis Robinson, Dr. Robin Rudd, John Pickering and Hugh Robertson.

The collaborations with those named above and the groups they represent have brought significant gains. Through public protests, parliamentary lobbies, judicial reviews, outreach activities and other initiatives, injustices have been highlighted, remedies sought and victories won. During the 1990s, the political acuity and fervour of asbestos victims support groups north of the border were key to actions taken by the Westminster Parliament. On 22 November 1995, Ian McKechnie from Clydeside Action on Asbestos, MP Tony Worthington, representing the Clydebank and Milngavie constituency, and Frank Maguire, a Glasgow-based specialist in asbestos litigation, gave

evidence to a Parliamentary lobby calling for the abolition of the much-reviled Compensation Recovery Unit (CRU) [3]. In November 1996, the CRU was reformed and compensators and not victims were made responsible for repaying “all relevant Social Security benefits, paid to the successful plaintiff in respect of his injuries” [4]. After devolution (1998), the efforts of the Scottish groups focused increasingly on Holyrood committees and Members of the Scottish Parliament. As Phyllis Craig explained:

“Devolution created a Parliament ready and willing to act in the interests of the victims of what is recognised and accepted as a shameful legacy of the country’s otherwise proud industrial heritage. What has been most encouraging is that support has been, for the most part, irrespective of party politics. The asbestos campaign groups have been relentless in their efforts and have achieved remarkable success in bettering access to justice in the Scottish Legal System. This has had an impact on those with an asbestos related disease, both with regard to civil damages and legislation affecting benefit entitlement.”

(See page 43: Twenty Years of Legal Changes in Scotland.)

Amongst the successes achieved in Scotland was the 2009 Damages (Asbestos-related Conditions) (Scotland) Act which re-established, in the face of the 2007 ruling of the House of Lords in the case of *Johnston v NEI international Combustion Ltd.*, the rights of pleural plaques sufferers in Scotland to claim compensation. The legislative consultations and bills needed to achieve this were the subject of fierce attacks by insurers who sought a judicial review, petitioned the Court of Session and even appealed to the UK Supreme Court (see page 60: Pleural Plaques and Neglected Social Justice Issues). They did not succeed and in 2016 Scottish sufferers of pleural plaques have been granted court-awarded compensation of up to £15,000; sufferers in England and Wales remain barred from bringing claims [5].

Over the last decade, the Asbestos Victims Support Groups Forum UK (the Forum) has provided “a unifying voice for asbestos victims” (see page 40: Asbestos Victims and the Ongoing Fight for Justice). With its members, supporters and partners, the Forum has challenged actions by government departments, Parliamentary bodies, British insurers and others that sought to undermine the legal and human rights of those affected by asbestos-related diseases. It is frightening to contemplate the injustices which could have been wrought had the Forum not contested the gross inequities proposed by those seeking to curtail the liabilities of negligent employers in the commercial and public sectors. The details recounted by Graham Dring, the Forum’s Chairperson, provide a salient reminder of the need to maintain a perman-

ent watching brief on the powers that be and “develop links with like-minded organisations and individuals in Europe and beyond.” As he so forcefully concludes: “This is a fight for justice, not sympathy – the betrayals of the past will galvanise us to secure justice now and in the future.”

Since the beginning of the 21<sup>st</sup> century, the Asbestos Sub-Group of the All Party Parliamentary Group on Occupational Safety and Health has provided the opportunity for asbestos victims, campaigners, trade unionists and other stakeholders to highlight systemic failings and judicial injustices experienced by those suffering from asbestos-related diseases to MPs and Members of the House of Lords (see page 36: Parliamentary Activity on Asbestos) [6]. A number of high profile successes have been achieved via “lobbying ministers, raising questions in the House of Commons, intervening in (and even initiating) parliamentary debates, and publishing policy papers” including:

- reducing delays in payments of Industrial Injuries Disablement Benefits due to bureaucratic blockages (2000);
- mobilizing Parliament to introduce the Compensation Act 2006 to reverse the iniquitous Law Lords decision in the case of *Barker v Corus (UK) plc*;
- the publication of the policy paper: *Asbestos in Schools – the Need for Action* (2012);
- the establishment of the Diffuse Mesothelioma Payment Scheme (2014);
- heightened awareness of the failure to act on widespread asbestos contamination following the circulation of the Asbestos Sub-Group’s report: *The asbestos crisis – Why Britain needs an eradication law* (2015).

Trade union representatives are actively engaged with the work of the Asbestos Sub-Group and, of course, other Westminster bodies; in addition, there are close working relationships between UK and international unionists which have helped raise the profile of asbestos in discussions at the EU Parliament and at international meetings such as the 2015 Conference of the Parties to the Rotterdam Convention (see page 53: Asbestos and the GMB; and page 55: Unite’s Asbestos Campaign: Asbestos – Banned but Not Gone; All Asbestos Causes Cancer). At home, the GMB and Unite unions have both been active in the Joint Union Asbestos Committee and worked closely with the Asbestos in Schools group. Through consultations with government departments, the development of asbestos guidance material for members, and collaborations with victims’ groups, union officials have made significant contributions to efforts to safeguard workers’ rights and improve occupational protection despite serious financial constraints and a hostile political climate.

As with Nancy Tait, the battle for asbestos justice was a personal one for Michael Lees, whose school-teacher wife died at age 51 from mesothelioma in 2000, just months after her condition was diagnosed.



Schoolteacher Gina Lees

Michael embarked on a fifteen-year quest to understand how an industrial disease could take the life of a teacher and what could be done to prevent other deaths. What he uncovered was “a scandal that remains unresolved after fifty years” (see page 46: Asbestos in Schools – A Fifty Year Scandal). In great depth and with a wealth of detail, he documents years of neglect and malfeasance by generations of civil servants and successive governments more afraid of public relations disasters than of cancer epidemics. Information gleaned from a wide variety of government sources as well as replies to Freedom of Information requests paints a damning picture:

- despite knowledge about the asbestos hazard, 85% of UK schools were constructed using highly friable products such as sprayed asbestos lagging and asbestos insulation board which contained the most toxic of all asbestos fibre types – amosite and crocidolite;
- asbestos-containing products used in schools built after the second World War are now deteriorating due to their age; much of the friable material is easily accessible to children;
- between 1980 and 2013, 308 school teachers died of the asbestos cancer, mesothelioma; for every asbestos death of a teacher “between two and three hundred people will die each year due to asbestos exposures experienced as children at schools during the 1960s and 1970s”;
- government policy on asbestos in schools is fatally flawed in its reliance on advice from

the Health and Safety Executive which in 2011 declared that as schools were “low risk,” pro-active inspections of local authority schools would cease.

Noting that “Britain has the worst incidence of mesothelioma in the world,” Michael wrote that “an increasing proportion of the deaths are amongst people who have never worked in high-risk occupations. It is reasonable to conjecture that a significant contributory factor is that generations of children in Britain have been exposed to asbestos at school.” Concluding his exposition, the author calls for an “honest assessment of the scale of asbestos contamination and the level of risk for school personnel and pupils,” and “radical measures... to halt the carnage that has been exacerbated by decades of misguided government policies.”

In the late 1960s a ground-breaking British TV series called “The Prisoner” was filmed in the Welsh village of Portmeirion. Week after week, the protagonist – or Number 6 as he was called – grappled with the Kafkaesque situation in which he found himself. This program came to mind when reading the contribution from Cenric Clement-Evans (on page 57) entitled: Right to Know: Asbestos in Schools Wales – a Long and Winding Road? When it comes to the issue of asbestos in Welsh schools, the Welsh government and the Westminster Parliament agree that neither one of them is responsible, with the former saying that as this is a health and safety matter it is not devolved and the latter adamant that the responsibility is devolved to Cardiff and not the Health and Safety Executive or the Department for Education. The Right to Know Campaign was started in 2012 to resolve the situation and via petitions, public meetings, discussions with Asbestos in Schools campaigners and consultations with ministers, members and bodies of the government in Cardiff has “raised awareness of the issue in Wales.”

The development of corporate [7] and legal strategies to avoid asbestos liabilities has been ongoing for nearly one hundred years. With every battle won for claimants, three more seem to loom large. Pleural plaques compensation which had been an established precedent for decades, was wiped out by insurer-driven litigation with an estimated saving of £1.4 billion for Britain plc [8]. While Scottish and Northern Irish sufferers have regained the status quo, those in England and Wales have not. In the fight to secure the rights of asbestos claimants, the expertise of legal professionals is of paramount importance. Several solicitors and barristers have achieved breakthroughs and while it would be inappropriate to name them here, their feats are detailed in issues of the newsletter. One of the most glaring inequities is the failure to secure government benefits and personal injury compensation for sufferers of asbestos-related lung cancer. According to the Health and Safety Executive:

- “Research suggests there are probably about as many asbestos-related lung cancer deaths each year as there are mesothelioma deaths”;
- “This implies there are currently in excess of 2,000 lung cancer deaths each year in Great Britain that can be attributed to past asbestos-exposure”;
- there were 285 cases assessed for Industrial Injuries Disablement Benefit in 2014;
- there were an estimated 96 cases of occupational lung cancer reported to the Health and Occupation Research Network by chest physicians in 2014;
- the much lower number of cases identified via the Industrial Injuries Disablement Benefit Scheme and the Health and Occupation Research Network highlight the difficulty in attributing individual cases to asbestos exposure [9].

In the article (on page 63) entitled: Asbestos Induced Lung Cancer – Proof of Causation, Barrister David Allan, QC examined the background to and outcome of a lung cancer test case brought against multiple defendants; previous cases which had reached trial had been against single defendants. In *Heneghan v Manchester Dry Docks Ltd. 2016 EWCA Civ. 86*, the Court of Appeal considered the claim brought for the premature death of James Heneghan who had been exposed to asbestos by multiple tortfeasors, six of which could still be sued. Although it was agreed that the exposure to asbestos “was sufficient to increase Mr. Heneghan’s risk of lung cancer about five-fold (more than satisfying the requirement to prove a doubling of risk),” the Court of Appeal’s verdict, following the Fairchild principle, found that the “liability of each defendant will be proportionate to the contribution to the risk of disease.” As the six defendants were responsible for only 35.2% of the asbestos exposure, the compensation recovered will be significantly reduced. The injustice of this outcome was not lost on the author:

“The lung cancer victim already faces a greater hurdle in proving sufficient asbestos exposure to satisfy the doubling of risk test. It frequently occurs that some tortfeasors responsible for a significant part of the asbestos exposure can no longer be sued. It will be a considerable injustice if a lung cancer victim, having satisfied the doubling of risk test by proving on a conventional basis that their cancer was caused by asbestos, can still only recover a modest proportion of their full loss.”

### **Mesothelioma: The British Disease**

The repercussions of Britain’s long-lasting love affair with asbestos have been disastrous. Annually, nearly three times as many Britons die from asbestos-re-

lated diseases as from road traffic accidents [10]. According to British researchers: “UK mesothelioma mortality is the highest worldwide” [11]. This dubious distinction has been confirmed by World Health Organisation (WHO) statistics which reveal that between 1994 and 2008 “the United Kingdom had the highest age-adjusted [mesothelioma] mortality rate, at 17.8 per million, followed by Australia, at 16.5 per million, and Italy, at 10.3 per million” [12]. During the 14 years covered by the WHO data, there were 13,517 UK deaths from mesothelioma; only the United States, a country with a population of 316 million, recorded more (17,062).

The transition that follows a mesothelioma diagnosis from a life of employment and family matters to one dominated by hospital tests and medical appointments is realistically described by Claire Cowley (see page 13: *The Cowley Family’s Journey with Mesothelioma*). In September 2012, her husband Paul was diagnosed with mesothelioma; he was 34 years old. Writing about the family’s new normality, she says:

“From May 2013 to date our lives have been lived in two or three month chunks up to Paul’s next Papworth [Hospital] appointment... It is very hard to explain though to anyone looking in on our lives what it is like to live with a terminal cancer diagnosis. Although Paul looks incredibly well he still has cancer.”

Paul and Claire play an active role in the Papworth Mesothelioma Support Group and have engaged in outreach activities to raise both public awareness of mesothelioma and funds for medical research [13]. As of January 2016, Paul’s latest CT scan showed that the tumour had not grown or spread. Nevertheless “mesothelioma does remain in Paul’s body and we know that it is incurable. One day, it will start to grow but for now we can only hope that day is a long way off.”

The experiences of mesothelioma warrior Mavis Nye underscore the difficulties faced by patients cast adrift by mesothelioma diagnoses (see page 16: *Mesothelioma Warrior*). But for her persistence, Mavis “wouldn’t even have known about the Keytruda trial as the Marsden doesn’t advertise their clinical trials.” As a result of her treatment at the Royal Marsden Hospital, she has experienced an “81% shrinkage with three marker tumours disappearing completely.” At the same time as she urges patients to seek out second medical opinions and explore all treatment options, Mavis highlights the importance of Clinical Nurse Specialists and the need for collaborative efforts to find a cure for mesothelioma. Concluding her comments, she writes: “the best way to protect future generations is to prevent hazardous asbestos exposures and find a cure for the unlucky ones, like us, who contract mesothelioma.”

Since 1990, medical awareness and treatment of mesothelioma in the UK has improved with progress

often driven by the efforts of medical professionals or impassioned citizens with first-hand experience of asbestos cancer. In 1997, Macmillan nurse Mavis Robinson established the UK's first National Mesothelioma Information Centre in Leeds; the following year, a national mesothelioma telephone hotline became operational. Mavis' pamphlet: *Mesothelioma: Information for people with Mesothelioma and their carers*, which first appeared in 1999, was extended and republished on numerous occasions. By the time she retired, 100,000 copies of the booklet had been distributed to patients, hospitals, hospices and specialist nurse teams [14]. A training scheme designed and implemented by Mavis to create and educate a network of lung cancer specialists on mesothelioma health care, diagnosis, clinical research, palliative care and medical treatment led to the creation of specialist nursing posts in asbestos hotspots such as Leeds, Manchester, Newcastle, Glasgow, London and Portsmouth.

Building on the work of nurse Robinson, in 2004, the Mesothelioma UK National Resource Centre, or Meso UK as it is commonly referred to, was opened (see page 18: Mesothelioma Clinical Nurse Specialists in the UK). In 2009, the formation of the Mesothelioma UK Charitable Trust gave a new financial grounding and security for the work of this nurse-led organisation dedicated to "improving the outcomes and experiences of those living with mesothelioma" [15]. By exploring online tools and working closely with the mesothelioma community of patients, clinicians, researchers and campaigners, Meso UK staff nurses support, educate and lobby on behalf of the injured. It is not coincidental that Consultant Nurse Liz Darlison, head of Meso UK, is a member of the local organizing committee of the International Mesothelioma Interest Group's Birmingham conference (May 2016) or that she was asked to present evidence at a Parliamentary hearing on mesothelioma on 22 March 2016. The expertise of this or-



Dean Fennell addressing Parliamentary seminar, 2013

ganisation is well-recognised as are the skills and compassion of its personnel [16].

Unfortunately over much of the last 25 years, advice given by doctors to mesothelioma patients was cursory and depressing: "put your affairs in order," some people were told, "there's nothing we can do for you," was the message others received. For more than a decade, the standard chemotherapy drugs used for mesothelioma treatment have been perimetrexed and cisplatin; in many patients, this protocol has not prolonged life to any appreciable extent. Finally, however, hope is on the horizon in the form of new drugs and immunotherapeutic approaches (see page 15: Mesothelioma – At a Turning Point in 2016?). According to Dr. Fennell "we are entering a golden age of research for mesothelioma – both translational and clinical. The implications are that we may see new standards of care emerging over the next few years at an accelerating rate."

UK researchers have the benefit of a mesothelioma tissue bioresource – aka MesobanK – housed at the Papworth Hospital NHS Foundation Trust, Cambridge. According to MesobanK's Project Manager Jacki Gittins "The long term objective is that the use of MesobanK's tissue samples will translate into novel treatments for patients with mesothelioma resulting in improved survival" (see page 23: MesobanK – A Mesothelioma Tissue Bioresource Now Open for Business).

The importance of research that translates findings from basic science into medical and nursing protocols to achieve meaningful health outcomes is one recognised by the UK's first mesothelioma charity: the June Hancock Mesothelioma Research Fund (JHMRF). Founded in 1997 in memory of mesothelioma victim June Hancock, the fund has now raised over £1.5 million "for research projects that aim to improve treatment and care for people with mesothelioma, and increase understanding of mesothelioma development and progression" [17].

Kimberley Stubbs, June Hancock's daughter, details some of the JHMRF's latest outreach activities, collaborations and support for investigations into: the use of radiotherapy for treating pain, the feasibility of adapting a proven gene therapy for treating blood cancers for mesothelioma patients and the development of new anti-cancer agents and immunotherapy delivery systems (see page 20: The June Hancock Mesothelioma Research Fund). On 24 March 2016, the JHMRF launched the Mesothelioma Handbook, a new resource for patients, carers and health professionals which contains essential information presented in an accessible manner [18].

Even though bureaucratic obstacles for the approval of new drug protocols can occasionally be overcome – e.g. "within months of successful melanoma trial data being presented, combination studies [with Merck's Keytruda (pembrolizumab)] [19] have now

commenced enrolment internationally for patients with mesothelioma” – at the current time, palliative care remains the most appropriate treatment option for many patients. Evidence shows that there are non-hazardous and relatively inexpensive interventions that can improve quality of life and reduce physical and psychological distress for people experiencing mesothelioma’s “severe symptom burden.” Drawing on thirty years of experience as a general practitioner and physician in hospice and hospital palliative care in the north of England, Dr. Helen Clayson highlights “the benefits of integrating palliative care and oncological care from an early stage” whilst arguing for high quality research to determine best practice for the treatment of those affected (see page 25: Palliative Care in Mesothelioma: Benefits and Challenges).

### **Asbestos: The Bigger Picture**

It would be comforting to think that more than fifteen years after Britain had banned asbestos, things were improving. Unfortunately, this is not the case as the analyses by Robin Howie reveal (see page 65: Estimation of Future Male Mesothelioma Deaths in Great Britain). With some serious number crunching, Robin presents shocking figures related to the effects of longer life expectancies and other factors on male mesothelioma fatalities:

“The calculations indicate that male mesothelioma deaths will increase progressively from about 11,000 between 2014 and 2019 to about 30,000 between 2045 and 2049. Such increases will be primarily driven by those aged between 80 and 89; but with a significant contribution from those aged 90+. It is estimated that total male mesothelioma deaths will be about 130,000 between 2014 and 2049 and will total about 180,000 between 1969 and 2049, about twice the figure given by Tan and Warren (2009).”

What is true on our shores is most likely true for other at-risk countries with aging populations. The cost of healthcare and social support which will be required by those affected is likely to be astronomical.

In their contribution to this issue of the newsletter (see page 62: Armley: “Too Close to Home”), Vanessa Bridge and Adrian Budgen marked the 20th anniversary of a landmark ruling which recognised the right to compensation of people exposed environmentally to asbestos. As children June Hancock and Arthur Margereson inhaled asbestos fibres liberated by manufacturing operations at an asbestos factory in Armley, Leeds. As a result, both of them contracted mesothelioma. Despite the corporate defendant’s intention “to contest these claims by any means possible, legitimate or otherwise... simply to obstruct the plaintiff’s road,” on 2 April 1996, the Court of Appeal upheld a claimants’ verdict. This case was reported in local and national newspapers, on radio

channels and in TV news programs; the determination of June Hancock to see this case through made her an inspiration not only to people who knew her personally but to others who had never met her. When she died just 15 months after the verdict, it was decided to establish the June Hancock Mesothelioma Research Fund in her memory [22]. The Court of Appeal ruling in this case stands as a testament to the rights of people everywhere who have been poisoned by the actions of negligent and greedy corporations.

Although, asbestos has caused Britain’s deadliest occupational epidemic, decisive action was not taken until long after many developed countries had outlawed the import, processing and usage of asbestos. It was only under the protective cover of an impending EU asbestos ban that in August 1999, Deputy Prime Minister John Prescott signed The Asbestos (Prohibitions) (Amendment) Regulations [20]. The highly political and protracted process which finally resulted in this legislation was played out against a global backdrop dominated by the World Trade Organisation dispute over the French asbestos ban. Through this and other actions, asbestos stakeholders had made clear their intention to fight any measures that could impact on global asbestos markets.

Despite all that is known about the human health effects of exposures to asbestos, two million tonnes of chrysotile (white) asbestos are still used every year. The asbestos industry’s evolving survival strategy remained a focal point in newsletter articles from 1990 onwards. In the paper “Battles over Chrysotile” on page 67, historian Geoffrey Tweedale delineates key stratagems wielded by those supporting the use of chrysotile (or chrysophiles as the author called them in a 2010 publication) [21] including:

- commercial influence on international agencies via the provision of funding for “scientific discussions and meetings”;
- distorted research and biased publications discounting the arguments and credentials of chrysotile’s critics;
- spurious advisory missions by industry-funded consultants.

During the 20<sup>th</sup> century, the Canadian asbestos lobby coordinated global industry action to protect sales. As with public relations campaigns mounted by the tobacco industry, the intention was to provide ammunition for the status quo to remain unchanged; in the absence of municipal, national, regional or global regulations, the trade in asbestos would remain unfettered. Concluding his commentary Geoffrey writes:

“The *Newsletter’s* strength has been to follow doggedly the chrysotile story as it has played out across the world. Its pages provide inform-

ation about the politics of the asbestos industry and the personalities involved... The *Newsletter* narrative shows why millions of tonnes of asbestos are – unknown to most people – still produced in the world.”

The *Newsletter* which began as a tool to collect and disseminate information transitioned to an instrument of change. As mentioned by several contributors to this issue, over the last 25 years *Newsletter* staff have worked hand in hand with victims’ groups, trade unions, cancer charities, medical associations, politicians and public servants on outreach projects, public meetings, political demonstrations, information sessions, parliamentary seminars and consultative exercises. Historic events which spring to mind include multiple demonstrations outside the Canadian High Commission and the world’s first ever asbestos protest outside a Russian Embassy. Britons have paid with their lives for the right to speak out about the asbestos hazard. It has been our duty to do so and will remain, well after the last *Newsletter* is published, incumbent on fellow citizens to continue the battle for asbestos justice.

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## THE COWLEY FAMILY'S JOURNEY WITH MESOTHELIOMA

Claire Cowley

Our journey with doctors and hospitals started in the summer of 2012 (or possibly earlier) when Paul had been to the doctors with a few problems he had, including haemorrhoids. He was given a blood test which found he was anaemic. As well as being prescribed iron tablets he was referred to Addenbrookes Hospital in Cambridge. After several tests with cameras up and down he was also given a CT scan to check for abnormalities. Later, he was referred for a further CT scan to cover more of his body.

In September 2012 we had been away on holiday for a week and came back to a letter from Addenbrookes referring Paul to Papworth Hospital, which is a specialist heart and lung hospital. From memory I think the referral letter said that there was something of concern showing on the scans of Paul's lung. Shortly after receiving this letter there was a call from Papworth for Paul to go in for a needle biopsy.

I will never forget our first visit to Papworth. It was the day cancer entered our lives. I don't think, up until that day, either of us had even thought about the possibility of Paul having cancer. I remember a doctor coming to talk to us before Paul was taken down for his biopsy. I can't remember what she was telling us but I clearly remember her turning to me and asking what I was concerned about. From that moment on, the word cancer was a part of our lives.

After Paul's biopsy we were introduced to Claire our Specialist Nurse who explained exactly what they had found and why they were concerned that Paul could have cancer. Claire has followed our journey with us and is still present for all our appointments.

Following Paul's biopsy we had, what I can only describe as the worst, most horrendous week of our lives waiting for the results. This involved telling family, friends and work colleagues. Support was abundant; we remained positive and hoped that it would be something else and not cancer.

Result day arrived and we travelled to Papworth along with my Dad, leaving our then 22 month old son Ethan with my Mum. Unfortunately, on that day the clinic was running late and we were seen after 45 horrendous minutes in the waiting room.

It was cancer. My husband had cancer and they thought it was something called mesothelioma which was caused by exposure to asbestos. I don't think any of us had heard of it and I'm not too sure really if we listened to much of what we were told for the rest of that appointment.

At that first diagnosis appointment, Paul was referred

for a PET scan at Addenbrookes, which would show up any cancer in his body. This was to check that there was no cancer anywhere other than where they had already discovered it. We returned to Papworth the next week for the results, which we were pleased to find out were good: cancer had been found nowhere else in Paul's body. At this appointment we were introduced to a surgeon. He was very surprised at what the needle biopsy had revealed and was not convinced that at Paul's young age (34) he could actually have mesothelioma. He wanted to go in and have a look and perform what they called a VATS biopsy [biopsy using video-assisted thoracoscopic surgery]. He would also introduce talc between the affected lung and the chest wall; this would stop any liquid forming there which could cause a problem. The procedure was scheduled for the week after – on 19 October 2012.

For the VATS biopsy Paul was expected to be in hospital for a few days. He had the procedure on the Friday and he was discharged on the Saturday! We did, however, have to return quickly on the Monday morning as they had sent Paul home without having an x-ray to check for air leakage before he was discharged. Luckily, all was fine.

This biopsy did establish that Paul definitely had mesothelioma. We believe the sampled tissue was checked by several different people and even sent to London to be looked at. It was therefore decided that Paul would be best to have radical surgery to remove as much as possible of the tumour. Paul had this surgery on Friday 23 November 2012. Again, he was expected to be in hospital several nights, maybe five to seven. He was home after three! I even remember commenting to the nurse "should he actually be coming home so soon." Paul has and never will (I'm sure) conform to any mesothelioma statistic.

Paul recovered extremely well from the surgery. Our son turned two on 4 December and he had a little party with some friends at a local soft play centre. Daddy couldn't help having a little play and was seen on hands and knees pushing a cosy coupé car round.

A few days later we returned to Papworth to see the surgeon for a check-up and also for Paul to meet with his oncologist. The surgeon had already told us that he was surprised with the progression of the disease from the time he performed the VATs biopsy to the day he did the radical surgery. He was therefore keen for Paul to start chemotherapy quickly.

Our first meeting with the oncologist turned out to be quite a heartbreaking and emotional time for us both.

It was decided that Paul was fit enough to have chemotherapy and it was best that he have it quite quickly – before Christmas!

Side effects of the chemotherapy could leave Paul no longer able to father children. As a couple with just one child we had always planned to have at least one other brother or sister for Ethan. Unfortunately, as Paul's cancer was categorised as incurable he was not eligible to have any sperm banked on the NHS. We did look into sperm banking ourselves but realistically we knew time was not on our side. Also, with the knowledge that Paul's cancer was incurable we were unsure about bringing another child into the world not knowing how long he or she would have a Daddy for. We both made the heartbreaking decision that we would have to leave our family as it was and Ethan would be an only child; a decision that was so hard to make and is still very hard to think about even now. Ethan is such a friendly, adorable little boy. He would have made a great big brother.

Paul started chemotherapy on 20 December 2012. The drugs used were pemetrexed and cisplatin. We arrived at Addenbrookes at the chemotherapy ward for 9am and didn't leave until 6pm. It was a very long day. Paul had a bad hives reaction to the pemetrexed and had to have a large dose of piriton, intravenously. Within half an hour of leaving the hospital, and while we were driving home, Paul started to feel very sick. I had to stop the car in a layby just before we reached home for him to be sick. Once we were home I called the hospital and they suggested calling our doctor. We did as they suggested and on call emergency doctors came to see Paul. They ended up visiting twice, as the first anti-sickness tablets they offered did not work and in the end they had to give Paul an injection. This lasted only until the next morning, when we returned to the hospital for them to give Paul some stronger anti-sickness medication. Paul stayed in hospital overnight for monitoring.

Christmas 2012 was not great. The side-effects of the first chemotherapy session were bad and even though Paul's sickness was controlled, he still felt very nauseous and tired. He had also pulled some stomach muscles and suffered badly with acid reflux. All of these things were corrected for the second cycle of chemotherapy.

Paul was admitted to hospital for his second cycle of chemotherapy, which happened three weeks after the first. He was to have six sessions in total, all three weeks apart. Luckily, the second session went well and with strong anti-sickness relief on board and other medication the side effects were not as severe as for the first. Tiredness, however, was quite bad and Paul would spend the first week after chemotherapy not really leaving bed or the house.

From December 2012 to April 2013 we lived our lives in three week blocks. Chemotherapy clinic for

check-up and blood test, chemotherapy day, the bad week or so, the good week and then back to the beginning. After cycle three Paul had a CT scan which suggested there was shrinkage and after six cycles another CT scan showed that the chemotherapy had done what it needed to.

At the end of April 2013 Paul turned 35 and we booked ourselves a week's holiday at Center Parcs to recover from the hardest six months of our lives. It was an amazing relaxing holiday with our little boy.

After the end of chemotherapy, Paul was referred back to Papworth for check-ups every two months and then after several "stable appointments" they changed this to every three months. At these check-ups we would see either the oncologist or one of his registrars. Paul would have an x-ray before the appointment and they would check this against previous x-rays. They would also listen to Paul's chest and ask him how he was feeling and about any side-effects or symptoms he was experiencing.

Paul's biggest symptom to this day remains his fatigue and now he has to have a daily afternoon nap just to make it through the day. On the odd occasion where he doesn't have this nap we have to ensure that we have an early night or that he definitely gets his nap the next day.

From May 2013 to date our lives have been lived in two or three month chunks, up to Paul's next Papworth appointment. As time has gone on and the more "stable appointments" Paul has had we have slowly managed to get our lives back on track. During Paul's diagnosis and treatment he worked where possible. It is very hard to explain though to anyone looking in on our lives what it is like to live with a terminal cancer diagnosis. Although Paul looks incredibly well he still has cancer. In October 2014 Paul decided that he needed to finish work. He had been working part time, but with severe fatigue (and an incredibly unsupportive boss) he decided it would be best to leave work and concentrate, in the times he feels well enough, on his family life and the things he likes doing most.



Over the last few months Paul has been experiencing an increased amount and frequency of pain in the area of his surgery scar and his affected lung. At his

check-up in November 2015 it was decided that because of this he would have a CT scan. He hadn't had one since May 2013 when his chemotherapy was completed.

Paul had his CT scan on 7 January 2016 and we returned to Papworth on 21 January for the results. We are very pleased to report that his scan showed good news. His mesothelioma had not grown and there

were no new areas. The report stated that the scan showed stable appearance with no evidence of disease progression. We are of course over the moon with this result given that fact he has now been treatment free for two years and ten months. Unfortunately though, mesothelioma does remain in Paul's body and we know that it is incurable. One day, it will start to grow but for now we can only hope that day is a long way off.

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## MESOTHELIOMA – AT A TURNING POINT IN 2016?

Dean Fennell, Professor of Thoracic Medical Oncology, University of Leicester  
President, International Mesothelioma Interest Group

Effective therapy for mesothelioma, remains a pressing unmet need; particularly, in the wake of the UK epidemic that is set to peak this decade and which will be recapitulated in other western nations and potentially worldwide, based on continued use of asbestos. In many ways 2015/2016 will be seen as a turning point in the history of therapeutic drug development for mesothelioma. The promise of novel, effective therapy is closer than ever before, and parallels the astonishing developments taking place across the landscape of anti-cancer drug development. Furthermore, the rate at which new therapies will emerge, is set to increase.

### Standard of Care for Mesothelioma and an Unmet Need in the Relapsed Setting

Treatment of mesothelioma is dominated globally by one approved drug combination, pemetrexed-cisplatin, the effectiveness of which was originally reported in 2003 by Vogelzang and colleagues. Their "randomised" study (a critical factor), confirmed that a combination of two chemotherapy drugs was better than one (cisplatin alone). Over the last decade or so, the field has been plagued with a *therapeutic plateau* not unlike that which predominated in the lung cancer field until the emergence of personalised therapy around the mid-noughties. Why was this, and what has changed to bring optimism to the field?

There are perhaps three key factors that retarded the development of the field over the last decade. Firstly, a lack of randomised clinical studies to reliably validate the efficacy of those drugs thought to exhibit useful activity. With the exception of remarkably potent drugs, randomisation is the only unbiased way to establish whether a new treatment incrementally improves upon the current standard. Secondly, there was a preponderance of empirical studies – i.e. clinical trials testing a range of novel agents, some molecularly targeted, but without any way of predicting who might respond and who might not, in order to achieve maximum benefit (the concept of personalised therapy). Thirdly, a lack of investment from the pharmaceutical industry, perhaps in part due to the

perceived rarity of mesothelioma as well as a lack of biological insight to help support novel clinical trial strategies. But this scenario has changed dramatically.

### Beyond the Therapeutic Plateau

At the end of 2015, the French academic MAPS trial confirmed for the first time, robustly, that the addition of an antiangiogenic agent (a drug which prevents the formation of new blood vessels, essential for mesothelioma growth) can significantly improve survival for patients with mesothelioma. In so doing, the MAPS trials *ended* the decade long therapeutic plateau. This study has for the first time shown improved survival (almost a decade after it was shown in lung cancer). Other major studies are underway to explore this anti-angiogenesis strategy, reflecting a growing interest by the pharmaceutical industry.

### The Rise of Immunotherapy

Harnessing the immune system to kill cancer is one of the most exciting developments at the frontier of anti-cancer clinical drug development. Earlier, in April 2015, Evan Alley presented on behalf of the Keynote study 28 clinical trial, data on the PD1 immune checkpoint drug Keytruda (pembrolizumab, Merck) in patients with relapsed mesothelioma. This drug showed a response rate of 28% and disease control rate of 76% in the relapsed setting and has subsequently led to studies in the US, Europe and beyond. Combining these classes of agent is feasible and has achieved ground-breaking activity in melanoma. Remarkably, within months of successful melanoma trial data being presented, combination studies have now commenced enrolment internationally for patients with mesothelioma. Randomised studies of anti PD1 immunotherapy are now planned in the UK.

Immunotherapeutic approaches are likely to extend beyond PD1 and CTLA4 as drug targets in the future. For example, Leicester along with collaborating centres in Italy, France, Belgium and Netherlands, have been funded by the EU to run a novel study of

dendritic cell vaccination for mesothelioma in the DENIM study. Led by Rotterdam's Professor Joachim Aerts, this approach involves programming a patient's own white cells (monocytes) to stimulate the immune system to attack mesothelioma. Results from promising initial studies are now to be explored in a multi-national randomised trial.

### **Stratified Medicine for Mesothelioma**

The second JLA (James Lind Alliance) research priority (see: <http://www.psp.nihr.ac.uk/mesothelioma/results>) relates to approaches that can personalise therapy for mesothelioma. In the lung cancer, breast or melanoma setting for example, since the discovery of activating somatic mutations in so-called driver oncogenes, we have seen a rapid growth in approaches that seek first to identify patients likely to respond to therapy (on the basis of their cancer genetics). This has proven to be extremely effective – rapidly changing practice and increasing survival for subgroups of patients. Mesothelioma presents a potential opportunity to do the same; however, we are only at the start of the process.

The mutational “landscape” of mesothelioma has been described through extensive DNA sequencing. What has been revealed, is a catalogue of mutations that could be potentially targeted. These include BAP1, one of the most recent cancer gene mutations to be identified and a possible gene implicated in

causing some mesotheliomas. Levine's group recently showed that EZH2 inhibition can selectively kill cancers harbouring the BAP1 mutation. This discovery has opened up the possibility of targeted therapy for this cancer. Likewise, the finding that NF2 (found in 50% of cases) might be a sensitiser of focal adhesion kinase presents another opportunity. Mesothelioma UK has recently funded a Leicester based research project to study stratified therapy of the most common mutation, CDKN2A (seen in over 70% of cases). What makes mesothelioma a promising candidate for personalised therapy is the very high incidence of driver mutations – contrasting with the low rate (5-10%) seen in lung cancer.

In summary, there is no doubt now that we are entering a golden age of research for mesothelioma – both translational and clinical. The implications are that we may see new standards of care emerging over the next few years at an accelerating rate. It is timely therefore that the UK is playing host to the International Mesothelioma Interest Group (IMIG) 2016 conference in May, featuring a breadth of specialists (scientists, clinicians, nurses, campaigners, funders, representatives of pharmaceutical and healthcare industries) from more than 30 countries. As chair of this IMIG 2016 conference, I am hoping this will be the catalyst to drive the next generation of collaborations and innovations in the field, for the benefit of patients afflicted with this terrible cancer.

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## **MESOTHELIOMA WARRIOR**

Mavis Nye

Mavis Nye has played a crucial role in the founding and maintenance of online mesothelioma support groups, consultations with British politicians, and outreach work with medical professionals, asbestos removal technicians and representatives of pharmaceutical companies. If you google the words “Mavis Nye and mesothelioma,” the search engine returns 4000+ hits. In her 2015 book *Meso Warrior: One Woman's Fight against Mesothelioma*, on her blog [1], in YouTube clips [2], on Facebook and throughout the digital community, Mavis remains on message: “We can fight this disease.”

For someone as eloquent as Mavis, we felt that her contribution to this issue of the newsletter would best be expressed in her own words. The following is an interview conducted with her (MN) by the newsletter's editor (LKA) in April, 2016.

### **LKA: When did your involvement with mesothelioma begin?**

MN: I was diagnosed with mesothelioma on 4 June 2009, after returning from a holiday in Spain; I was

67 years old. My husband Ray and I had been touring in our motorhome for two months, but when we got home I had problems breathing and was rushed to A&E to have seven litres of fluid drained from my lungs. That is when I was told that I had mesothelioma and had three months to live. Although most of what I read online confirmed what I had been told, there were some people who had defied the odds. I swore I would fight back against my disease – and I did.

### **LKA: How did you contract this disease?**

MN: Ray worked at Chatham Dockyard as a shipwright. I shook out and washed his work clothes which were covered with powder which I thought was ordinary dust. Forty-eight years later I was told I had mesothelioma and was given three months to live.

### **LKA: What treatments were you offered?**

MN: The first chemotherapy I received started in October 2009 and was Cisplatin and Alimta. That worked great for fifteen months. In January 2011,

treatment with Cisplatin and Alimta was stopped as the disease was progressing. On 13 October 2011, I was put on the NGR-hTNF [3] clinical trial at Maidstone Hospital; either this treatment didn't work for me or I received the placebo as a scan showed renewed tumour growth. On 29 November 2011 I began a course of six sessions of treatment with Cisplatin and Alimta. Although, I had to stop after just four sessions because the treatment affected me so badly, the tumour growth had stabilised. However, a scan in January 2012 showed disease was progressing. In that month, I was offered the last place on the ADAM trial at St. Barts but I turned it down as it would mean another biopsy and the possibility of receiving "treatment" with a placebo. On 9 January 2012, I began treatment with GemCarbo chemotherapy (Gemcitabine and Carboplatin) at Canterbury Hospital, near where I live. This ended on 26 April 2014 when scans showed tumour growth again.

At the end of April 2014, I was told I had reached the end of the road; there were no further chemotherapy options. Through my work on the Saatchi Bill (The Medical Innovation Bill), I met Professor Dean Fennell. He mentioned to me that the Royal Marsden was starting a trial that might suit me. I asked an oncologist to refer me and she did. Since 2014, I have been on a phase 1 immunotherapy trial of the drug Keytruda (MK-3475) which blocks the interaction of a substance called PDL-1 with a PD inhibitor. I have had 81% shrinkage with three marker tumours disappearing completely. To access this treatment, I need to travel to the Marsden every two weeks to get my infusion. I will have to keep that up for the rest of my life but I can at least now talk about a life. I feel so well and I'm getting stronger as the months go by.

**LKA: The names of these drugs trip off your tongue; it seems you are pretty knowledgeable about mesothelioma.**

MN: You have to be. If I had not pushed for a second opinion and spent hours on the internet and online communicating with other people, I would not have found my way through the mesothelioma treatment jungle. If it wasn't for my persistence, I wouldn't even have known about the Keytruda trial as the Marsden doesn't advertise their clinical trials. Prior to my being accepted onto Marsden's Keytruda trial, I was being told there were only Phase 1 or 2 trials available; neither of these were suitable for me.

**LKA: Do other patients have to fight for the appropriate treatment?**

MN: I have lost track of how many people I have advised of their right to seek a second opinion. In February 2015, another Meso Warrior, when diagnosed with mesothelioma, was told that the hospital treat-

ing him "did not do trials, just tried and trusted methods." He was told to go home and make a will. Fortunately, he didn't accept this death sentence and did his own research as a result of which he was accepted on a TRAP [4] trial at St. Bart's Hospital in London. Currently, he is doing very well.

**LKA: How can things be improved?**

MN: I would urge the medics not to give up on us – there are centres which have expertise in the treatment of mesothelioma. Mesothelioma patients are willing to travel if it means they get the best treatment. The support of Clinical Nurse Specialists (CNSs) is crucial not only for the patient but for his/her relatives. More meso CNSs would make a big difference to the patients' experience. Although the introduction of portals via NHS Choices and ClinicalTrials.gov [5] has made accessing information about clinical trials easier more needs to be done to empower patients.

**LKA: I am aware that you will be speaking to delegates attending the upcoming International Mesothelioma Interest Group Conference in May 2016. What will your message be to them?**

MN: As patients we have a right and a need to have all the information presented to us regarding potential treatments and/or trials. Our doctors have to understand this is a collaborative process. We urge them to do everything they can to ensure that more research is done and that every option is pursued with all stakeholders, including pharmaceutical companies and crowdsourcing sites, to progress this work. The Holy Grail for all Meso Warriors is a cure for this deadly cancer. Remembering that most people have asbestos fibres in their lungs and that these fibres can initiate carcinogenic processes which result in mesothelioma, we believe that the best way to protect future generations is to prevent hazardous asbestos exposures and find a cure for the unlucky ones, like us, who contract mesothelioma.

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<http://www.nhs.uk/pages/home.aspx>  
ClinicalTrials.gov website:  
<https://clinicaltrials.gov/ct2/search>

## MESOTHELIOMA CLINICAL NURSE SPECIALISTS IN THE UK

Liz Darlison, Macmillan Mesothelioma Nurse Consultant,  
Mesothelioma UK and University Hospitals of Leicester

The Mesothelioma UK National Resource Centre was launched in 2004 with financial support, initially from Macmillan Cancer Support and later from industry colleagues, the Mick Knighton Mesothelioma Research Fund and generous private donations. To secure the centre's long term future the Mesothelioma UK Charitable Trust was established in 2009 and the new charity immediately became fully responsible for securing sufficient income to support the resource centre's activities. The financial independence of becoming a charity meant Mesothelioma UK has been able to continually grow and develop. Through integrated working practices the charity now significantly compliments and supports UK health care providers to meet the needs of people living with mesothelioma, particularly with regard to the provision of specialist nursing posts in the UK.

Clinical Nurse Specialist (CNS) posts began to emerge in the National Health Service during the 1990s predominantly in palliative care services. A large review of NHS cancer care (Department of Health 1995) recognised their value and there began the suggestion that all cancer patients should have

access to their own cancer Clinical Nurse Specialist. Guidelines and frameworks since have contained clear support for the growth in number of tumour site specific cancer nurse specialists. The fifth and most recent census of the specialist adult cancer nursing workforce in the UK (Macmillan Cancer Support 2014) showed there are 3,088 cancer nurse specialists in post which represents a 10% interim increase. It is understandable, given the obvious difficulties, that the census does not explore the challenges of providing specialist nursing for patients living with rarer cancers and no mesothelioma nursing posts were included in the report. Mesothelioma UK accepts there are challenges but is committed to providing equitable access to specialist nursing care and specialist support for people living with mesothelioma, their families and carers.

Through the early years (2004-11) Mesothelioma UK provided funding for one Nurse Consultant based within its host NHS trust, the University Hospitals of Leicester. Following the launch of the charitable trust it took two years to reach a degree of financial security felt necessary before funding for a second meso-

### **Current Mesothelioma UK Services and Activities**

**The Mesothelioma UK charity is a national specialist resource centre dedicated to improving the outcomes and experiences of those living with mesothelioma. To achieve this the charity:**

- **Provides funding for Mesothelioma Nurse Specialists based in centres of excellence across the UK and hopes to increase the number of posts significantly over the next 5 years.**
- **Employs a Citizens Advice Bureau specialist mesothelioma benefits advisor**
- **Provides funding for research dedicated to mesothelioma**
- **Is recognised as the UK's provider of specialist mesothelioma information**
- **Operates a specialist freephone helpline**
- **Collates UK clinical trial availability and promotes equitable access**
- **Maintains a comprehensive website**
- **Distributes a quarterly newsletter**
- **Holds regular conferences and educational events for patients, carers and health care professionals**
- **Delivers an accredited course in mesothelioma (in partnership with The Royal Marsden School)**
- **Campaigns to raise awareness about the dangers of asbestos**
- **Supports national data collection for mesothelioma**

thelioma nurse specialist was provided. Papworth hospital in Cambridge appointed this second Mesothelioma UK nurse specialist in late 2011. Cardiff followed in late 2012 and Portsmouth in 2013. Mesothelioma UK currently supports mesothelioma specialist nursing posts in Portsmouth, London, Bristol, Oxford, Leicester, Sheffield, Manchester, Northumbria and Glasgow, and funding for an additional three posts has recently been advertised which will take the total to twelve.



Mesothelioma UK nurses at Parliamentary asbestos seminar, 2016

Mesothelioma UK has used the current NHS structure to develop a “hub and spoke” approach to specialist mesothelioma nursing. Thankfully, the volume of people diagnosed with mesothelioma is not sufficient to warrant every NHS trust establishing a mesothelioma specific nursing post but the country is conveniently divided into twelve Strategic Clinical Networks (SCNs); regional posts are therefore feasible. A service level agreement (SLA) between the host NHS trusts for each of Mesothelioma UK supported post holders is prepared and signed by both parties. Providing the conditions of the SLA are met the funding is ongoing and guaranteed.

The SLA outlines expectations for the role locally (within the host trust), regionally (within the SCN) and nationally (supporting Mesothelioma UK core activities). Local expectations include coordinating

the care of a caseload of patients and acting as keyworker. Regional responsibilities require the CNS to set up and run a regional patient support group, provide educational opportunities for health care professionals, promote clinical trial availability and knowledge, high profile asbestos awareness and to share widely across the network the resources and activities of Mesothelioma UK. Finally, national responsibilities require the post holder to actively participate in the Mesothelioma Nurse Action Team (MNAT), a group established and facilitated by Mesothelioma UK, provide cover for the Mesothelioma UK help line and take a lead on developing an area of Mesothelioma UK’s services.

Group support has proved essential to the “hub and spoke” approach to specialist nursing in mesothelioma. The nurses meet 4-5 times a year. Each meeting contains educational updates about clinical trials or treatment advances, individual projects are reviewed and reflective accounts of experiences are exchanged and discussed. In between meetings the team are involved in a lively flow of communication, via a variety of social networking resources, emails and the telephone.

The Mesothelioma UK vision is to support at least one mesothelioma specialist nurse in each of England’s 12 Strategic Clinical Networks and then to mirror this in Wales, Ireland and Scotland. The charity predicts a minimum of 18 specialist mesothelioma nursing posts will be required to provide equitable cover across the UK and will endeavour to achieve this, funding permitting, over the next five years.

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# THE JUNE HANCOCK MESOTHELIOMA RESEARCH FUND (JHMRF)

Kimberley Stubbs, daughter of June Hancock,  
Chair and Trustee of the June Hancock Mesothelioma Research Fund

I am not a medic or a researcher – I am simply an ordinary person left devastated by what asbestos did to my family. Nor am I alone in that – many thousands of other families are bereft too. Many more will be in the future.

So, being able to do something positive in the face of such tragedy is a privilege, and a privilege that is afforded to me by some wonderful people that dedicate their time freely and with genuine commitment to change the face of treatments and outcomes for mesothelioma patients. Together, we are the JHMRF – aka “Team Hancock” – and after 19 years we remain determined in our objective to fund high quality peer reviewed mesothelioma research.

## **I want a cure....BUT?**

I want a cure because the pain and suffering human beings endure as a result of exposure to asbestos is cruel, distressing, heartbreaking and intolerable. And for those left behind it stays with you forever. It is haunting.

BUT, and more importantly at this stage of medical knowledge and expertise, I want to quickly see better outcomes and treatments for sufferers. To achieve this, we have to look at new therapies to improve survival as well as innovative treatments for symptom control in our research.

The JHMRF takes pride in often funding the “building blocks” for ongoing and future research, striving to build a long term collaborative pool of mesothelioma researchers and knowledge. Everything has to start somewhere.

To say I am proud of what we have achieved so far is an understatement. We started out after my Mum June Hancock’s death from mesothelioma in 1997 with a target of £40,000. Nineteen years later we have raised in excess of £1.5 m! Very sadly, the vast majority of this money has been raised by those mourning the loss of a family member or friend or work colleague to asbestos disease.

## **Our Research – Recent News**

### **The SYSTEMS Study**

*Is radiotherapy useful for treating pain in mesothelioma? Recipient of the JHMRF’s Brother Peter Fellowship, Dr Nicholas MacLeod, conducted a multicentre study to find out.*

Patients with mesothelioma may suffer from pain, which in some cases can be severe and difficult to treat with painkilling drugs. Radiotherapy has been given for a number of years to attempt to relieve pain

but there is very little evidence to support this use. In addition, giving radiotherapy in this situation is complicated by the fact that mesothelioma can affect large areas of the lining of the lung. If radiotherapy is given to the entire lung, this can be associated with side effects that may negate any potential gains in terms of pain control.

The SYSTEMS study was a multicentre study performed in the UK in which patients with mesothelioma received a standard dose of radiotherapy over 5 days to the area of pain. The patients were followed up for 12 weeks and the number of patients who responded to radiotherapy was recorded. The study was open to recruitment between June 2012 and December 2013. In total, 40 patients were recruited from cancer centres in Glasgow, Edinburgh and Sheffield. Fourteen patients had improvement in their pain five weeks after the radiotherapy, with five patients having a complete resolution of their pain. No changes in other factors such as breathlessness and quality of life were detected in the course of the study but this could be explained by the relatively small number of participants.

Dr MacLeod commented:

“The improvement seen in pain control in this study is encouraging. The SYSTEMS study was the largest study ever to look at radiotherapy for pain control in mesothelioma. The study would not have been possible without the support of the JHMRF and I cannot thank the charity enough for awarding me the Brother Peter Fellowship which enabled me to carry out this work.”

The main results from the study were recently published in the Journal of Thoracic Oncology.

- The full paper may be read online at: [http://journals.lww.com/jto/Fulltext/2015/06000/Is\\_Radiotherapy\\_Useful\\_for\\_Treating\\_Pain\\_in.12.aspx](http://journals.lww.com/jto/Fulltext/2015/06000/Is_Radiotherapy_Useful_for_Treating_Pain_in.12.aspx)
- A PDF version of the paper can be downloaded at: [http://www.junehancockfund.org/wp-content/uploads/2015/08/SYSTEMS\\_Report.pdf](http://www.junehancockfund.org/wp-content/uploads/2015/08/SYSTEMS_Report.pdf)

## **More JHMRF Funded Mesothelioma Research Projects**

*The last call for research proposals was a very important one for the June Hancock Mesothelioma Research Fund: the fund awarded over £450,000 to support two important new projects and two fellowships.*

The award process produced seven excellent applications that were sent out to carefully selected expert reviewers around the world for an assessment of their scientific merit and likely benefit to patients.

The process culminated with a meeting of the JHMRF Scientific Advisory Board, at which all the applications were discussed and the external reviewers' comments considered. After lengthy discussions two were identified as top choices. Funds available were insufficient to support two projects so it was decided to fund one project – SYSTEMS 2 – fully and the other – an immunotherapy project – for the first year.

SYSTEMS 2 will continue the work started by the Brother Peter Fellowship holder Dr MacLeod in Edinburgh to study the role of radiotherapy in symptom control. The study comprises a randomised controlled trial where patients with mesothelioma-related pain receive either standard dose radiotherapy or a higher dose of radiotherapy to see if a higher dose can bring about an improvement in pain control. Recruitment for the study is taking place in several centres throughout the UK. The plan is to recruit a sample of 144 participants over two years. It is the first study of its kind in mesothelioma and will hopefully give further insight into the optimal management of pain in this disease.

This work is likely to have the most immediate impact on patient care as advances in radiotherapy technology make it timely to investigate whether this widely available treatment can be used routinely in mesothelioma. Dr MacLeod said *“I'm delighted to continue the partnership with the June Hancock Fund and to have the opportunity to take this work forward to the next phase.”*

Dr Astero Klabatsa, a molecular biologist (then) based at King's College London, received a JHMRF project grant for the first year of her immunological study. She investigated the “CAR T-cell” approach that has recently achieved positive results for patients with blood cancers.

She completed her experiments in August 2015. Astero found that the new genes did give the immune cells the ability to attack mesothelioma cells and she also showed that it is feasible to grow the cells in the laboratory to produce a sufficient “dose” of cells that could be used to treat an adult patient. A paper reporting the results of the study is currently under review for publication.

A novel method of treating patients with modified T-cells is currently being tested in head and neck cancer. This study is nearing completion; if the results are promising, funding will be sought for a study in mesothelioma that would deliver immunotherapy directly into the space between the lungs and the pleura where the mesothelioma develops, through an in-dwelling pleural catheter. The study would test

whether the modified T-cells boost the patients' existing immune cells to attack mesothelioma cells and destroy them.

Two fellowships were awarded in 2015: The Stennett Fellowship has supported a doctoral study at the University of Birmingham led by Professor Gary Middleton. His research fellow is Dr Suzanne Graef.

This Fellowship will deliver the first comprehensive analysis of myeloid derived suppressor cells (MDSCs) in mesothelioma and the effects of therapies aimed at targeting them. These cells can influence the body's immune response to cancer cells. This fellowship offers a unique training opportunity in translational cancer immunology in a stimulating research environment: Professor Middleton was recently awarded £697,470 by the National Institute of Health Research, Efficacy and Mechanism Evaluation Programme to study the activity of a new drug (Ruxolitinib) in combination with standard chemotherapy for mesothelioma. The JHMRF, in partnership with the University of Greenwich, also funded another a PhD fellowship led by Professor Adrian Dobbs to take forward work on the total synthesis of anti-cancer agent JBIR-23 that began with the Steve Lee Fellowship. The compound will be refined and tested to confirm its activity against a range of mesothelioma cell types and its potential for development as an effective treatment agent.

The JHMRF is thrilled to be in a position to be able to support these exciting new research projects. Founding Trustee Dr. Kate Hill who manages the research activity of the fund commented *“Thanks to the generosity of our donors over £1.5 million has been raised in the 18 years since the fund was founded in June's memory; these latest awards will take us close to over £1million of that total sum being disbursed to research teams across the UK. **We are a small charity but our growing portfolio of research proves that we can make a difference.**”*

### Travel and Educational Grants

The JHMRF awards up to 10 travel grants each year. Applications are considered from researchers and health care professionals to support travel to conferences where applicants will either present papers or speak to a poster exhibit. In certain circumstances, grants may also be awarded for educational purposes; for example, for a study visit to an academic centre of excellence or to attend a course. Applications for co-sponsorship with other organisations or institutions are welcome. Individuals may apply for up to a maximum of £500 in any one year period. These grants have been very well received and appreciated by successful applicants. Reports of the conferences attended by JHMRF travel grant holders can be found on the website: <http://www.junehancockfund.org/2015/research/lily-presents-to-south-african-conference/>

### **The James Lind Alliance**

The JHMRF were delighted to participate in the research priority setting project conducted by the James Lind Alliance. Trustee, Dr Kate Hill was a member of the steering group. The project brought together patients, clinicians and patient organisations in a partnership to investigate the most important research questions for mesothelioma research. Top priorities were submitted to the National Institute for Health Research (NIHR) and a themed call for research proposals followed. More information about the Mesothelioma PSP and copies of key documents including the final report can be found on the James Lind website: [http://www.jla.nihr.ac.uk/priority-](http://www.jla.nihr.ac.uk/priority-setting-partnerships/mesothelioma)

[setting-partnerships/mesothelioma](http://www.jla.nihr.ac.uk/priority-setting-partnerships/mesothelioma)

### **Action Mesothelioma Day**

The JHMRF continues to actively support and take part in this annual national day of awareness raising and support. We had a great turn out to our popular “Meet the Experts” event in 2015 and we look forward to repeating that success this year on Friday 1 July 2016 at Weetwood Hall, Leeds. Watch our website for further information and updates.

For more information on this or on any of our work please visit our website: [www.junehancockfund.org](http://www.junehancockfund.org) or email the Chair directly at: [info@junehancockfund.org](mailto:info@junehancockfund.org)



JHMRF, Action Mesothelioma Day, 2015

**We Are Making a Difference**

**Thank you to all who make it possible.**

# MESOBANK – A MESOTHELIOMA TISSUE BIORESOURCE

## NOW OPEN FOR BUSINESS

Jacki Gittins, Project Manager of Mesobank

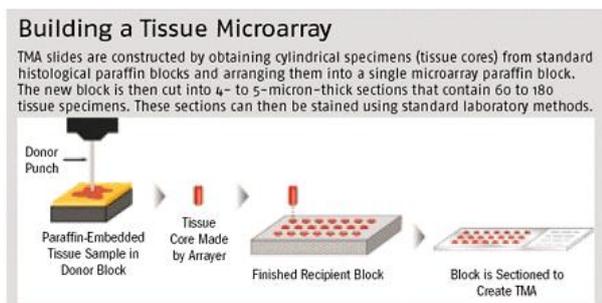
Mesobank is a mesothelioma tissue bioresource which has been given a favourable opinion by a Research Ethics Committee; it follows the “Guiding Principles” laid out by the National Cancer Research Institute Confederation of Cancer Biobanks [1] and the MRC Operational and Ethical Guidelines on “Human Tissue and Biological Materials for Use in Research.”[2]

Mesobank supplies researchers with human tissue and blood samples to use in mesothelioma and asbestos related research.

There are a number of strands to Mesobank – A) a Tissue Microarray being built with Formalin Fixed Paraffin Embedded (FFPE) tumour samples which had been archived for diagnostic use, B) prospective collection of blood, pleural fluid and tumour samples from patients newly diagnosed with mesothelioma and C) the creation of novel cell lines.

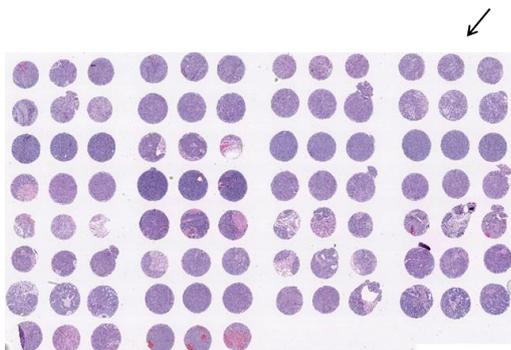
### A) Tissue Microarray (TMA)

A TMA is an incredibly useful tool for researchers. Small cores (0.6mm diameter) are taken from the tumour samples (FFPE) of many hundreds of patients and remounted in one block. This block is then thinly cut to give researchers access to multiple samples on one slide (see diagram below).



Adapted from an illustration by Mark A. Gabrenya

90 cores of tumour tissue available on a single slide



There are samples from over 800 patients in the laboratory being cored, ready for inclusion in what will become the largest mesothelioma TMA available to researchers across the world.

Having multiple tumour samples available from many different patients in such a concise format allows researchers to use large numbers of samples in an identical manner very quickly and easily; a single experiment can be undertaken simultaneously on many hundreds of samples.

Mesothelioma tumour samples, stored as FFPE blocks, have been gathered from the archives of NHS Hospitals across the UK – from Aberdeen to Portsmouth and all points between. This gives a huge breadth of samples and encompasses all subtypes of the disease. Each sample is accompanied by a clinical data set including subtype, age, gender and treatment given. Mesobank has obtained approval from the Health Research Authority Confidentiality Advisory Group (HRACAG) to exchange data with the National Cancer Registration Service (NCRS). The NCRS already collects data from every patient diagnosed with cancer in England including treatment (chemotherapy, radiotherapy and surgery) and outcomes. We also expect to include relevant data from any previous analysis undertaken which we hope will reduce repetition and assist researchers move forward more quickly with their work.

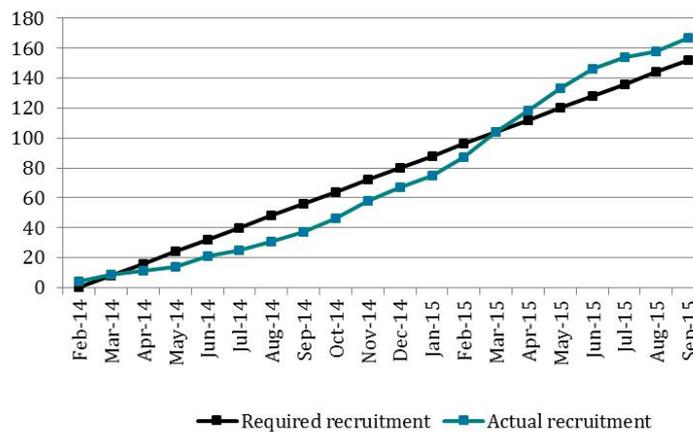
### B) Fresh Tissue Samples

Patients presenting to clinics in 14 hospitals in the UK are approached for consent to donate samples to Mesobank. Where possible, tumour, blood and pleural fluid samples are taken and processed and stored, using SOPs (Standard Operating Procedures) written to maximise the usefulness of the sample set. Tumour samples are stored at -80°C after treatment with RNAlater. Each tumour sample is examined by a specialist Consultant Histopathologist at Papworth Hospital. Tumour content, necrosis and size are checked; samples are returned to long term storage once it is confirmed they are suitable for use.

Blood and pleural fluid samples are spun and aliquots stored at -80°C. Plasma, serum and buffy coat samples are available for research as well as DNA.

All samples are despatched with an anonymous data set which can be extended to include more treatment and outcome data in time. The diagram below shows monthly recruitment.

MesobanK - monthly recruitment figures



All samples are stored in a central biorepository under controlled conditions to optimise and maximise their usefulness. When needed they are despatched to researchers directly using temperature controlled transport and dedicated couriers.

### C) Cell Lines

Tumour cell lines are essential tools in the effort to develop therapies against cancer. The currently available mesothelioma cell lines were generated from pleural fluid and biopsy specimens collected over two decades and consequently have been maintained in culture for considerable durations. Keeping cell lines for such long terms may mean that their effectiveness as tools for developing new anticancer treatments are reduced, so cell lines have been developed from new sources. MesobanK is working with two other organisations on this, and to date 26 novel cell lines are available for research use. The demand for aliquots of these cell lines is high, as we expected, and discussions are underway with regard to expanding their number.

### Research Review Process

A process to review applications from researchers now in place allows UK researchers funded by members of the Association of Medical Research Charities (AMRC) to be quickly assessed and receive samples quickly. Researchers not funded by AMRC and those from outside the UK are assessed by a Research Advisory Board external to MesobanK. Lay and scientific members use “terms of reference” to assess applications and categorise their priority in the event of insufficient samples being available immediately. We do not expect applications to be refused unless we are unable to support the research due to it being outside the remit of the approval given to MesobanK by the Research Ethics Committee. It is our aim to support mesothelioma research as widely as possible – applications and outcomes are regularly assessed and we will review our processes if we are unable to fulfil a request for samples.

### Open for Business....

A number of research groups have requested tissue and blood samples collected by MesobanK; samples of blood and tumour have been used by academics in a UK University and in separate work, cell lines have been used for research into novel medicines.

The samples currently being collected will support research over the next year at least and we hope that MesobanK will facilitate and stimulate new ideas and avenues of research into mesothelioma that will lead to further research projects. We are open to discussions regarding bespoke sample collections and would invite researchers interested in using existing or future samples to contact us so that we can discuss requirements as early as possible.

The long term objective is that the use of MesobanK tissue samples will translate into novel treatments for patients with mesothelioma resulting in improved survival. Furthermore, the infrastructure established for MesobanK will provide a lasting legacy for mesothelioma research going forward.

MesobanK aims to become a self-funding biore-source, gaining income from cost recovery fees which will allow the collection of samples to continue. Such fees are calculated to cover the costs of procuring, processing and storing samples.

MesobanK has been funded by the British Lung Foundation and the Mick Knighton Mesothelioma Research Fund and is hosted by Papworth Hospital NHS Foundation Trust.

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<http://www.oncoreuk.org/pages/documents/HumanResearchTissueBanksGuidingPrinciplesv611-06.pdf>

Medical Research Council (MRC) Operational and Ethical Guidelines on Human Tissue and Biological Materials for Use in Research. [http://www.mrc.ac.uk/pdf-tissue\\_guide\\_fin.pdf](http://www.mrc.ac.uk/pdf-tissue_guide_fin.pdf)

## PALLIATIVE CARE IN MESOTHELIOMA: BENEFITS AND CHALLENGES

Helen Clayson MD, Chair/founder Cumbria Asbestos Related Disease Support  
Author of the Mesothelioma Handbook 2016

Imagine an intervention for people with mesothelioma that offered the following advantages:

- improved quality of life;
- less physical and psychological distress;
- fewer inappropriate interventions, especially at the end of life;
- reduced caregiver stress and burden.

Moreover, consider that this intervention was non-toxic, relatively inexpensive, applicable from diagnosis and available to all patients, regardless of their clinical condition, age, and whether or not they were receiving chemotherapy or other cancer treatments at the same time. Suppose also that this was an evidence-based approach recommended in government policies and by the medical regulatory body, the General Medical Council [1-4]. Actually, such an intervention does exist. It is, of course, palliative care.

Mesothelioma, with a median survival of 8.5 months from diagnosis [5], satisfies the NICE criterion for an end-of-life condition [3] and the National Lung Cancer Audit (NCLA) 2014 Mesothelioma report [5] states that “all treatments in mesothelioma are palliative” (i.e. not curative). The NCLA report also sadly confirms that median survival has not improved in recent years despite advances in diagnostic techniques and oncological interventions; the majority of people who are diagnosed with mesothelioma will die within a year of the diagnosis. A small proportion, those with early epithelioid mesothelioma and good performance status (a measure of general physical function), are most likely to benefit from modern chemotherapy in terms of improved symptom control and/or longer survival. However, the benefit is usually modest and the reality is that currently there is no cure for this dreadful disease.

The challenge is to understand why palliative care is still not a routine component in the management of people who have mesothelioma and to look at how this situation might be changed. The NCLA 2014 report revealed that 36% of people with mesothelioma do not have any form of anti-cancer treatment – so how are these patients, over a third of cases, cared for? Firstly, we need to understand what is happening concerning access to palliative care for people with mesothelioma. Despite emphasising the palliative nature of all treatments for mesothelioma, the NCLA report had one glaring omission: it completely failed to include any data related to palliative care. This was a major missed opportunity and should be recti-

fied in future audits. Surely it would not be too onerous for hospital trusts to report information relating to palliative care as part of the NCLA exercise? The additional data collection should include details of referrals of people with mesothelioma to palliative care and pain management services, hospital admissions for control of symptoms, and deaths in hospital. An in-depth review of medical records of 80 people with mesothelioma between 1998 and 2001 revealed that only 49% were referred to palliative care, and that in most of these cases the referral occurred within the last 8 weeks of life [6].

We know that people with mesothelioma suffer a severe symptom burden in their final months of life. The medical records review revealed that 91% suffered from pain and 96% from breathlessness; another study showed that pain in mesothelioma was more severe than in lung cancer and that psychosocial distress was also greater [6,7,8]. Whilst we do not know the extent of current access to palliative care for people with mesothelioma, those of us involved with asbestos victim support groups continue to hear many distressing accounts from bereaved relatives of unsatisfactory symptom control and end of life care. There are acknowledged problems across the UK regarding equity of access to palliative care services [8]. However, it is not difficult to make a special case for people with mesothelioma. The severe nature of the physical and psychological suffering in this condition should ensure that all these patients receive palliative care as and when needed.

The problem with variable quality of care was also identified in the recent James Lind Alliance (JLA) stakeholder consultation on research priorities in mesothelioma. People with mesothelioma, their families, other informal carers and healthcare professionals were surveyed to gather their concerns about diagnosis, treatment and care. The consultation was designed to “identify and prioritise ‘treatment uncertainties’ that are defined as research questions about the effects of a healthcare intervention for which there are no up-to-date, reliable, systematic reviews of research evidence.” Wide-ranging responses were received, mainly written as narratives rather than as specific research questions. Analysis of the 453 survey responses resulted in 52 unanswered research questions that were deemed to fit the criterion that they related to an “intervention” that could be tested by rigorous scientific methods. However, 46 other questions were developed from responses covering issues that were deemed to be “out of scope.” [9,10] Most of the “out of scope” responses related broadly

to problems that had been experienced in the care of patients. These ranged from delays in diagnosis and treatment and lack of information to variable access to palliative care. Thus, although the JLA final report identified a range of highly appropriate biomedical research priorities that all related to “interventions,” the consultation was prevented by its restricted focus from addressing a major issue, that of variations and inadequacies in care, as identified by patients and carers.

Modern palliative care developed from the 1960s when the late Dame Cicely Saunders was appalled by the suffering of terminally ill cancer patients, many of whom died in severe pain. Perhaps this partly explains the continuing notion, common to patients and some doctors, that palliative care is synonymous with terminal care. Now, however, the benefits of integrating palliative care and oncological care from an early stage are increasingly being recognised [11]. A study in lung cancer revealed that early introduction to palliative care is both acceptable to patients and results in improved quality of life [12]. In this study the patients continued to receive oncological treatments in line with usual practice. A surprising finding was that those patients who were referred early gained an extended survival of around 2 months. This is around the same survival benefit in general terms as that offered by chemotherapy in mesothelioma. A retrospective analysis determined that the aspects of palliative care (differing from standard oncological care) that accounted for the benefits were: “relationship-and rapport-building, addressing symptoms, addressing coping, establishing illness understanding, discussing cancer treatments, end-of-life planning and engaging family members” [13]. Integrating palliative care with oncological care allows patients to realise these benefits whilst allowing cancer specialists more time to concentrate on their interventions.

Research funding in mesothelioma is disproportionately low compared with that for lung cancer, and lung cancer is disadvantaged compared with cancer in general [14]. Funding for research into palliative care in mesothelioma, considering that potentially all patients with mesothelioma could benefit from it, is negligible. A recent literature search for randomised controlled trials in mesothelioma identified 48 studies of which only one investigated palliative care [10]. Currently, in the UK there are only two palliative care studies that specifically relate to mesothelioma. These are the RESPECT-Meso trial [15] that is looking at the early introduction of palliative care, similar to the Temel study [11] mentioned above, and the SYSTEMS trial [16] that is investigating the use of low dose local radiotherapy for the control of chest pain. It should be emphasised that mesothelioma charities are making significant contributions to funding for both these trials; Mesothelioma UK and HASAG (Hampshire Asbestos Support and

Awareness Group) in the first case and the June Hancock Mesothelioma Research Fund in the second.

In order to alleviate suffering through the best possible control of physical and psychological symptoms we need to understand exactly what that entails in terms of clinical expertise and resources. A lot could be improved simply by utilising existing knowledge, by increasing palliative care education of healthcare professionals and by empowering patients and their families to request palliative care.

However, in order to determine what defines best practice in the palliative care of people with mesothelioma it is necessary to develop high quality research. In terms of cost-benefit, palliative care studies are considerably cheaper than drug-related studies; they are much quicker to achieve results and those results have the potential to benefit the majority of patients with mesothelioma. There is a need to determine, for example, the most effective methods for control of pain and breathlessness, how to manage the reactions to diagnosis, how to facilitate the transition from anti-cancer treatment to end of life care and how to achieve a “good death” in mesothelioma. In practical terms the overriding priority is to persuade funding bodies to pay as much attention to palliative care research as they do to studies relating to disease-modifying or curative treatments. There is an undeniable need for new initiatives designed to support palliative care studies in mesothelioma.

In mesothelioma palliative care should be routinely integrated with oncological care. Importantly, it should be accessed at an early stage in the illness for all patients, and particularly for those 36% unable or unwilling to receive oncological treatments. Finally there is a need to counter the claim that introducing palliative care is a “nihilistic” approach. On the contrary, palliative care is an intervention that affirms life and reduces suffering. Over 10 years ago the World Health Organisation [17] acknowledged that palliative care should be utilised at an early stage in cancer treatment and explained this as follows: “this change in thinking emerged from a new understanding that problems at the end of life have their origins at an earlier time in the trajectory of disease.” Given the devastating nature of mesothelioma, the short survival for most patients, and the severe suffering experienced by patients and their families, palliative care should be available from the time of diagnosis as a matter of course.

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### Making a Difference



Clockwise from top: Protest at Canadian High Commission, London 2010; Demonstration at Russian Embassy, London 2013; Michael Lees (Asbestos in Schools Group), Brussels 2012; Tony Whitston (Asbestos Forum) and Dr. Greg Deleuil (Asbestos Diseases Society of Australia), Manchester 2009

# CEMENTING ASBESTOS WITHIN THE PUBLIC CONSCIOUSNESS

Laurie Kazan-Allen

Dr. Greenberg noted in the preface to this newsletter that as British engineers and technicians began exploring the commercialisation of asbestos, marketing and public relations specialists were developing techniques to increase demand for their products. One such tool was a 1930s publication entitled: “The Making of Asbestos-Cement Roofings as seen by W. Heath Robinson.” The commissioning of cartoonist Heath Robinson by Asbestos Cement Building Products Ltd., a subsidiary of Turner & Newall, to illustrate this slim promotional volume was inspired. Heath Robinson’s unique style and whimsical approach had endeared him to generations of Britons. By the First World War, his name had entered the popular lexicon as shorthand for overcomplicated machinery and ingenious contraptions for achieving simple tasks.

The cartoons on the following pages document the complete production cycle of asbestos-cement roofing from the operations at Turner & Newall’s ten South African mines to the grinding of the ore, the mixing of the treated fibres with cement, the drying process, the manufacture and finishing off of the roofing sheets. The anonymous author of the text accompanying the cartoons left it to the artist to portray “the various processes of manufacture in his own inimitable way.” It is notable that despite knowledge about the occupational asbestos hazard as detailed in the medical press in the 1920s and the report by Merewether and Price [1] published in 1930 (at about the time when the artist would probably have visited the Manchester asbestos cement works), there were no face masks, dust suppression equipment or protective clothing in any of the drawings.

The written contents reinforced the positioning of asbestos as a boon to mankind and the products sold by Asbestos Cement Building Products Ltd. as being “of the finest possible quality.” The last few pages of text veer away from the general praise of all things asbestos to the specific advantages enjoyed by customers of the company which employed specialised and research chemists who were “constantly working with a view to improvement – if improvement is possible.”

The final artwork in the volume was not by Heath Robinson. It was designed during the early years of the 20<sup>th</sup> century by illustrator John Bernard Partridge, well-known for his cartoons in Punch magazine, who was knighted in 1925 by Prime Minister Stanley Baldwin. This illustration, nicknamed “Lady Asbestos,” first appeared in a 1918 issue of the in-house magazine produced by Turner Brothers Asbestos

(after 1920 to be yet another Turner & Newall subsidiary). This image was reproduced countless times in corporate publications and papers written about the company. Positioned within a Grecian setting and leaning on an Ionic column is a classically draped female figure – Partridge drew Britannia in a similar way for his political cartoons – holding aloft a shield to protect herself from a raging conflagration. The word asbestos in capital letters is emblazoned upon the shield. Looking down upon this scene, as Gods from Olympus, are male figures labelled shipbuilding, engineering, building and electricity. Two lions, symbolising the British Empire, stand watch over these modern deities. The caption on this highly decorative allegory is “asbestos” written in Cyrillic script. Should readers have been in doubt about the objective of this publication, this image constitutes a final reminder of the importance of the industrial asbestos sector to the British way of life.

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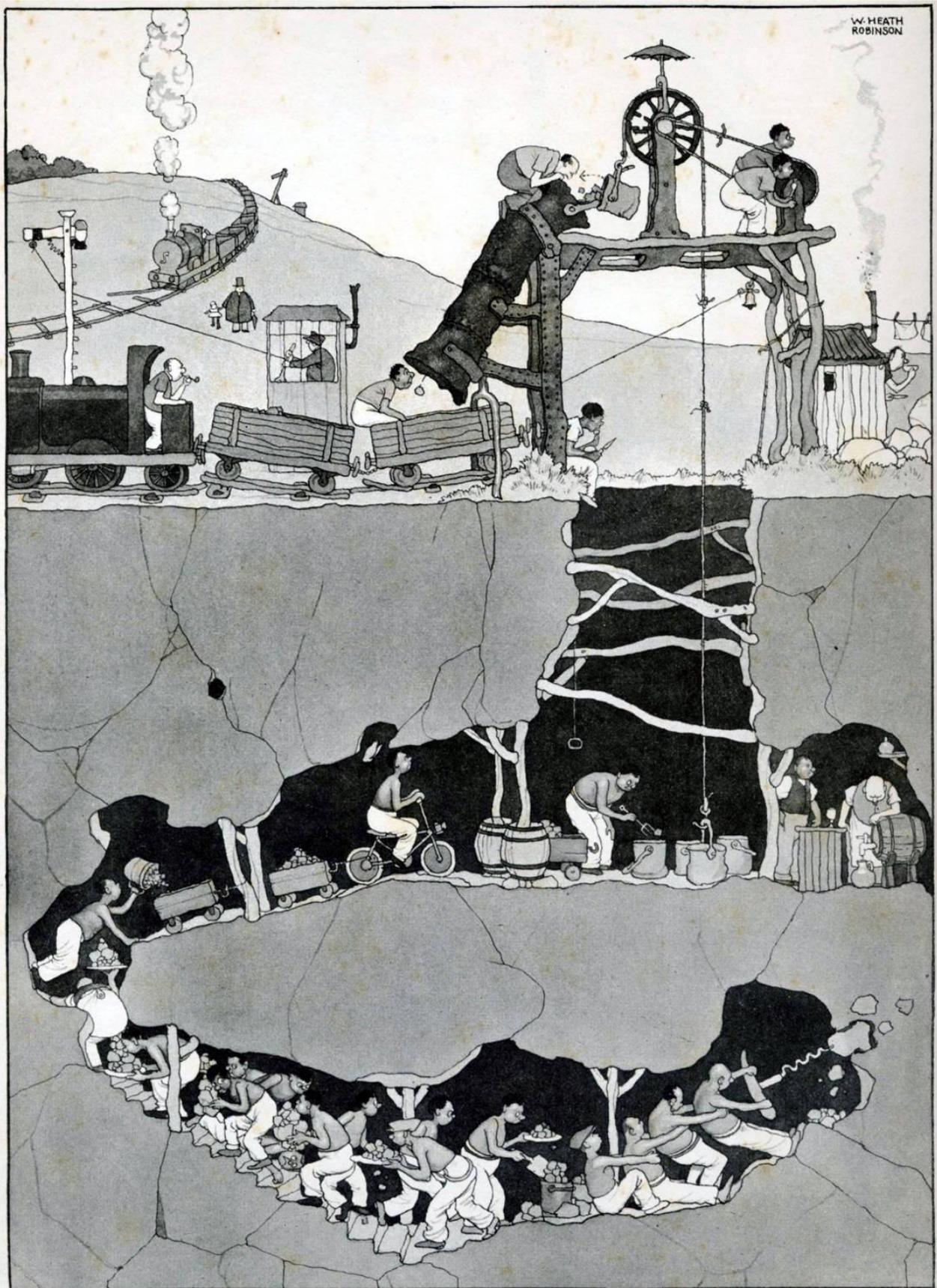
## HEATH ROBINSON AND ASBESTOS CEMENT

Geoffrey Beare,

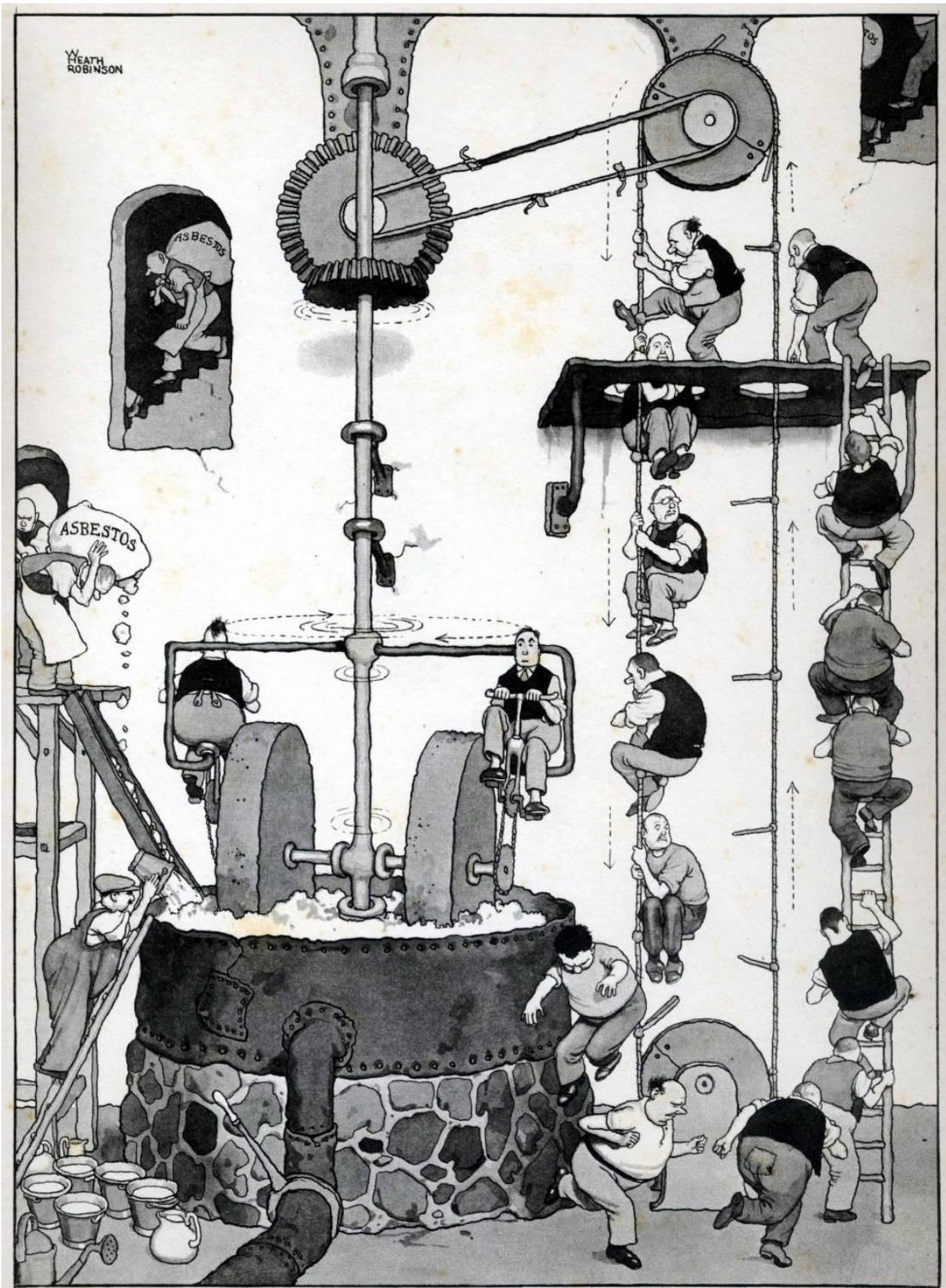
Trustee, the William Heath Robinson Trust

Heath Robinson’s name has entered the language to describe any contraption made from whatever comes to hand, usually held together with knotted string, but who was he? William Heath Robinson (1872-1944) was a brilliant artist whose initial ambition was to be a landscape painter. However, in order to make a living he turned first to book illustration then to humorous drawing. From 1920 until his death in 1944 humorous drawings for advertising made up a large part of his commercial work. He was particularly in demand for pictures showing his concept of how the product was made, such as his drawings for Asbestos Cement Building Products Ltd. Heath Robinson was invited to visit the works at some time between 1929 and 1932 in preparation for making a number of drawings for this promotional book in which “he portrayed the various processes of manufacture in his own inimitable way”. The book was finely printed by photogravure on heavy, deckle-edged paper and tied in embossed card covers with a silk ribbon.

W. HEATH  
ROBINSON

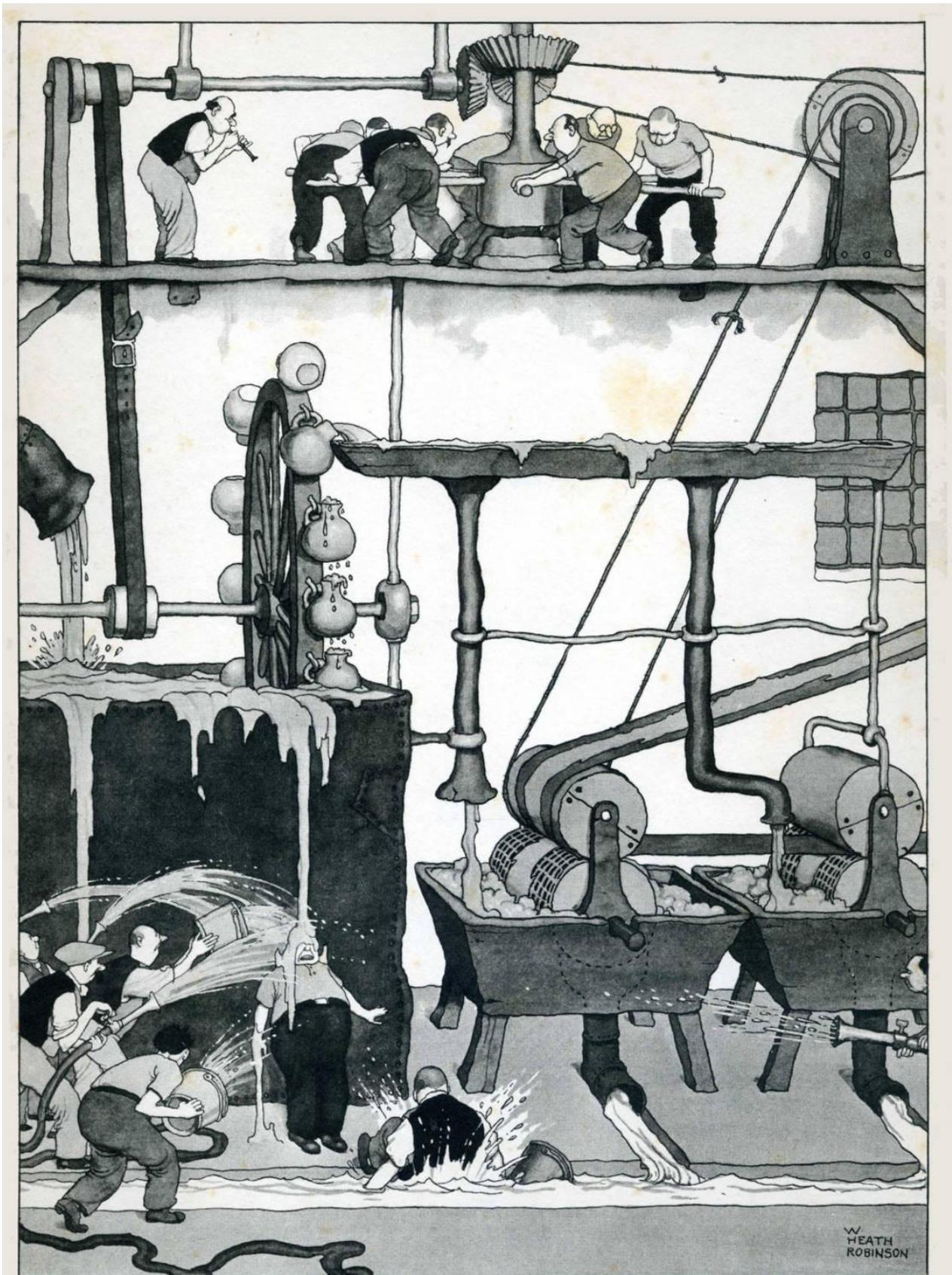


THE MINING AND TRANSPORT OF RAW ASBESTOS



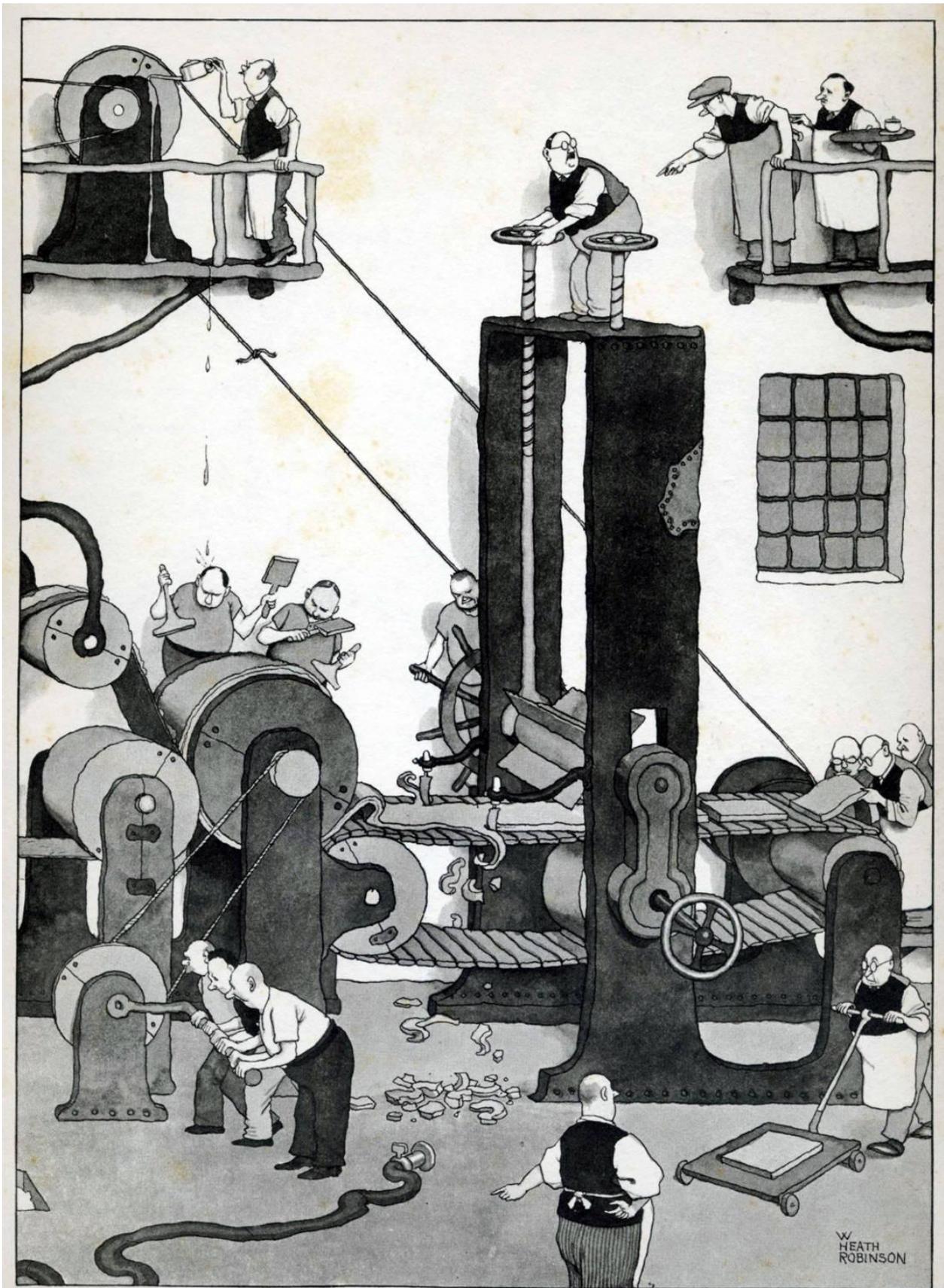
A PATENT DOUBLE ACTION GRINDER  
FOR MASHING THE ASBESTOS FIBRE





W  
HEATH  
ROBINSON

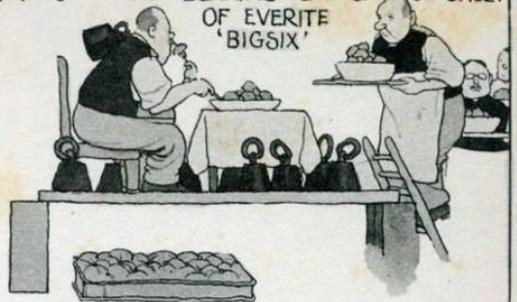
POWERFUL MACHINERY FOR CONDUCTING THE MIXTURE TO THE CYLINDRICAL SIEVES FOR DRAINING OFF THE WATER, WHENCE



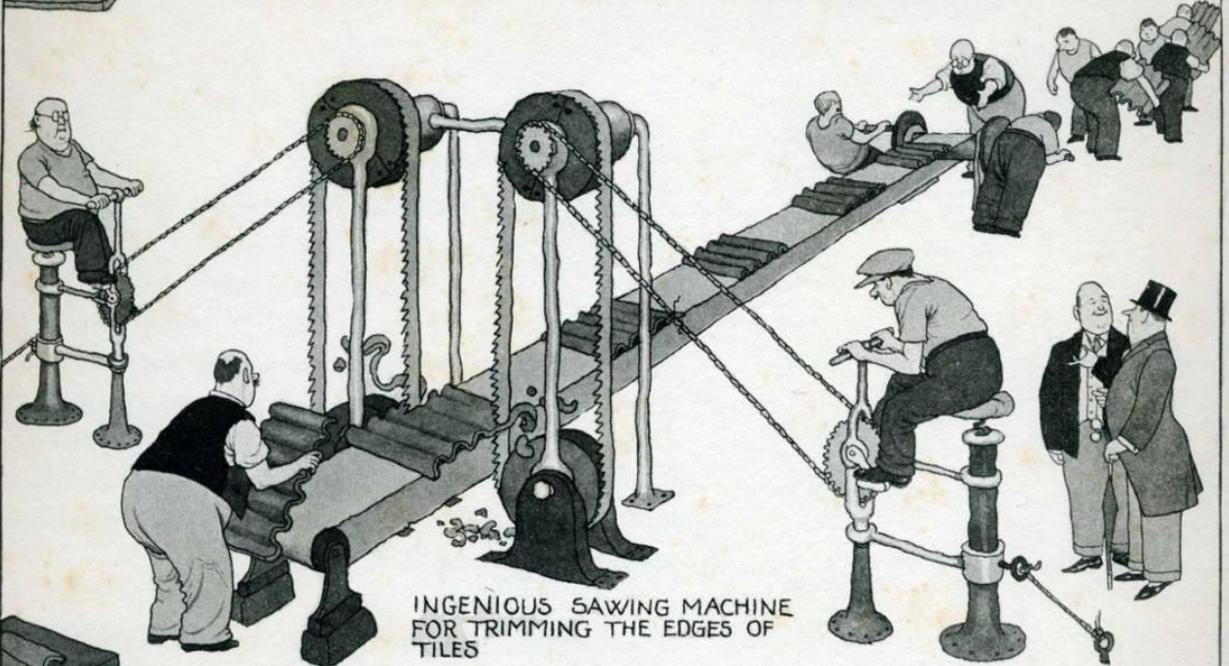
A THIN FILM IS CONVEYED TO THE CYLINDER UPON WHICH THE SHEET IS BUILT, AND THIS FINALLY TO THE CUTTING MACHINE.

W. HEATH ROBINSON

ASCERTAINING WEIGHT BEARING CAPACITY OF SHEET OF EVERITE 'BIGSIX'



MOULDING A TRAFFORD TILE BY HAND



INGENIOUS SAWING MACHINE FOR TRIMMING THE EDGES OF TILES



TESTING THE HARDNESS OF A TRAFFORD TILE

TESTING A TILE FOR RESISTANCE TO HEAT AND FIRE

TESTING A CONSIGNMENT OF TRAFFORD TILES FOR IMPERVIOUSNESS TO RAIN BEFORE DISPATCH

AN INTERESTING AFTERNOON IN THE FINISHING DEPARTMENTS OF AN ASBESTOS CEMENT FACTORY.



ἄσβεστος

## PARLIAMENTARY ACTIVITY ON ASBESTOS

Ian Lavery MP, Chair, All-Party Parliamentary Group on Occupational Safety and Health

In the UK a number of Parliamentarians meet three times a year to discuss asbestos-related issues. They comprise a sub-group of the All-Party Parliamentary Group on Occupational Safety and Health, set up around 15 years ago to examine issues concerning asbestos exposure, both in terms of prevention of such exposure and support for sufferers of asbestos-related diseases.

There are around 40 members of the asbestos sub-group, drawn from both the House of Commons and the House of Lords, and representing each of the four largest parties. The sub-group meetings are also open to representatives of victims support groups, unions, law firms specialising in asbestos litigation and campaigners. Usually around 60 people attend each meeting. I chair the meetings and the British Trades Union Congress provides the administrative support for the sub-group.

Every year the sub-group holds a seminar on current issues. This is organised by Laurie Kazan-Allen, the Editor of the British Asbestos Newsletter and covers both UK and international issues. The most recent such event took place on 22 March 2016 and was dedicated to the discussion of one specific subject: UK funding, or lack thereof, for asbestos cancer research. Patients, medical experts and leading re-

searchers presented evidence and engaged in discussions with Parliamentarians; calls made by mesothelioma sufferers Trevor Barlow and Mavis Nye for a long-term, coordinated funding strategy were unanimously supported.

However, what matters is whether the asbestos sub-group makes a difference – its track record indicates that it does. There have been a number of high profile successes over the past fifteen years that show that it can be effective, regardless of the political colour of the government.

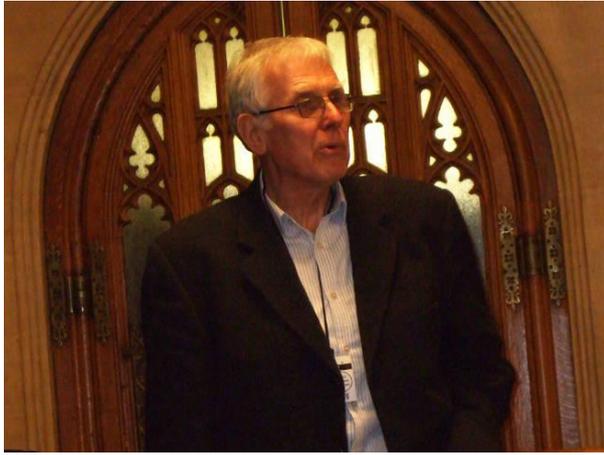
The sub-group works by lobbying ministers, raising questions in the House of Commons, intervening in (and even initiating) parliamentary debates, and publishing policy papers. It also acts as a coordinator of the activities of others.

In the first year of its existence it challenged the government on the amount of time that it was taking to assess mesothelioma claims under the state Industrial Injuries Disablement Benefit Scheme. Within a few months of it being raised with ministers the process was overhauled and payments were usually approved within a few weeks of diagnosis.

The sub-group also managed to get the government to effectively overturn a 2006 court decision on how



Representatives of the Asbestos Forum and Mesothelioma UK pictured prior to the Asbestos Sub-Group meeting, 22 March 2016



Trevor Barlow, March 2016



Mavis Nye, March 2016

compensation in mesothelioma cases was calculated through the introduction of a new law to specifically deal with the issue.

That was only one of a number of occasions where the sub-group has successfully lobbied ministers to achieve a change in legislation.

The biggest success was securing a totally new compensation system for those mesothelioma victims who could not sue their employers because, since their exposure, the records of their employers' insurance could no longer be traced. It was estimated that this applied to almost one in ten claimants and meant that they were losing out on their entitlement to compensation of, on average, almost £200,000 each. In 2008, the sub-group published a report on the problem and called for a scheme to be set up, paid for by the insurers. In early 2010, after a series of meetings with ministers and questions in both the House of Commons and House of Lords, the government issued a consultation paper on the exact proposals that the sub-group had proposed. Despite a change of government in May of that year, the new administration, following pressure from the sub-group, finally agreed to bring forward legislation to set up the scheme. This was brought into law in 2014 and, as a result, anyone who is diagnosed with mesothelioma and who had previous occupational exposure is entitled to get compensation from the insurance industry without being required to establish the identity of their employer's insurer. Already, hundreds of people have benefitted from this.

However, it is not only in cases of compensation where the sub-group has been successful; it has also lobbied hard on prevention. In 2010, the government stopped funds for a hard-hitting advertising campaign that was being run by the state prevention agency, the HSE. It was aimed at tradespeople like carpenters and plumbers who were often exposed to asbestos. The chair of the sub-group met with ministers and raised the issue in the House of Commons,

eventually getting an assurance that the campaign would be reinstated. The sub-group has also been in the forefront in calling for increased funding for research aimed at finding a cure for asbestos cancer and improved treatment options.

Not all of the sub-group's activities have been restricted to the UK. It has lobbied for a worldwide ban on asbestos and also offered support to those in other countries who are currently being exposed to asbestos or who are already suffering the consequences of exposure.

The sub-group is now looking at the future and, this year, is launching its most ambitious ever campaign. It wants to see the eradication of all asbestos from the UK by 2035. In a new booklet, it shows that simply managing existing asbestos to try to prevent exposure is not enough and this strategy is clearly failing, with an estimated 1.3 million workers being put at risk every year. The only solution is to have a planned and properly managed programme of safe removal and disposal of all asbestos. This is a massive task, given that there are around six million tonnes of asbestos still in place and it can be found in over half a million workplaces. However, radical asbestos removal is essential if mesothelioma is to be eradicated by the end of this century. The campaign has the full support of the asbestos victims groups, the British trade unions, many of the law firms, and a growing number of medical and safety professionals.

I am immensely proud to chair the asbestos sub-group. It has proven its worth over the past 15 years by making a real difference to the lives of those suffering from asbestos-related illnesses and by seeking to prevent further exposure. But there is a lot more to do, and working in partnership with others, it is now preparing for the final challenge: the eradication of all asbestos-related disease through the eradication of all asbestos.

## NANCY TAIT AND THE PURSUIT OF JUSTICE

William McDougall, Lecturer at Glasgow Caledonian University

I consider it as both a great privilege and an honour that I was provided with the opportunity to research and explore the (OEDA) archive at the University of Strathclyde library. For in doing so I was able to engage with at least some of the large rich collection of material brought together by Nancy Tait, the founder of the world's first asbestos victims' support group. First as the Society for the Prevention of Asbestosis and Industrial Diseases – SPAID (1978-1995) – and then as the Occupational and Environmental Diseases Association – OEDA (1995-2008) – Nancy fought to gain justice for the victims and families of asbestos sufferers. As the widow of a mesothelioma victim who had died in 1968 due to intermittent exposure (her husband William Tait came into contact with asbestos while inspecting telephone cables for the Post Office) she fought a four-year battle with the Post Office and DHSS for compensation. However, it was the recognition of asbestos as a collective problem that turned her into a tireless activist and a formidable and determined foe of the asbestos companies. She had a steely determination and her dogged persistence not only attracted the ire of her opponents but gained her allies as well in the UK and further afield. Two early supporters of Nancy were Lord Plant of Benenden and Lord Avebury (Liberal winner of the famous Orpington by-election). They helped her in 1976 publish a booklet “*Asbestos Kills*” and crucially gain a Churchill Fellowship. This allowed her to travel to Europe and North America researching asbestos. In the USA she met environmental activists such as Barry Castleman (whom she rode on a motorbike with) and returned to the UK convinced that attitudes around asbestos were complacent. She provided advice to the TUC, forced T & N to raise its payments to widows and came into contact with Petra Kelly, co-founder of the German Greens. With a growing interest in environmentalism, Nancy increasingly focused on white asbestos (chrysotile) used in products with which the general public came into contact.

SPAID was founded in 1978 after the initial idea of creating a trust was considered and rejected and the fledgling organisation survived initially with hardly any resources and only volunteer support. Nancy's sister carried out the book-keeping free of charge, a SPAID trustee, Ted Beckett, of the Post Office Sanatorium, who was also a source of great strength and support did the accounts and Nancy – who was not paid a salary by SPAID – used her free travel pass to attend meetings and visit victims and their families. At one stage she managed to have someone seconded for nine months to SPAID from National Westminster

Bank, claiming that it was due to SPAID having an account with the bank. It is more likely to have been the result of Nancy's persistence and powers of persuasion. Even SPAID's office equipment was provided by sympathetic supporters. The Fire Brigades' Union (FBU) donated a typewriter and volunteers using buckets collected funds for SPAID. Unsurprisingly, SPAID struggled financially and gained little attention in its early years but still had some notable successes with its first legislation success in 1981. Nancy gained further success providing support and advice to Alice Jefferson, who was to become the central figure in *Alice – a Fight for Life*, the 1982 Granada TV documentary that greatly damaged the reputation of asbestos usage in the UK. However, SPAID received little to no credit for its role in this project. In retrospect, Nancy regretted the involvement of Alice and believed it would have been better for her health not to have been involved in the TV production. Nevertheless, the increased publicity aided the cause of campaigners against asbestos.

Often stubborn, Nancy was quite prepared to fall out with anyone and often did; but this “genteel stubbornness” was used to benefit the pursuit of the rights of victims. However, from reading private correspondence in the OEDA archive it is clear that she was prepared to learn from others and adapt her tactics (though she might not necessarily let them know this) and she did rely on key allies for advice. In 1984 and again supported by the FBU, SPAID gained substantial funding from the Greater London Council (GLC). This led to a dramatic increase in the number of victims of asbestos that SPAID could help as bigger premises and extra staff were acquired. Incredibly, SPAID managed to be in profit for a number of years as Nancy built and kept a reserve in case funding was lost. She hoped that SPAID would provide research which would lead to the prevention of not only asbestos-related diseases but other industrial diseases. SPAID of course wanted to support the victims of asbestos and their families but was keenly aware that there was no cure for mesothelioma. Nancy wanted what she considered the “needless deaths from asbestos products” ended. Despite the purchase of a transmission electron microscope, SPAID and then OEDA never realised these wider ambitions of becoming prominent research-based organisations able to support the fight against not just asbestos but other substances injurious to health in the workplace and wider environment. More precarious funding after the GLC was abolished in 1986 and less media interest in asbestos until the mid-1990s

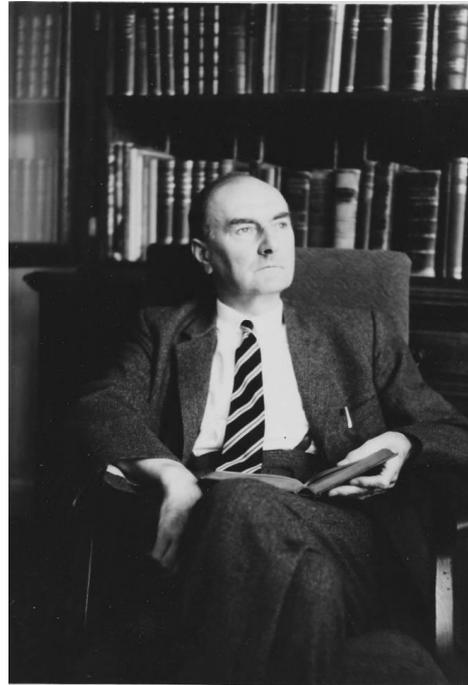
restricted Nancy's more ambitious plans for her organisation. Indeed the situation became so bleak at one point that Nancy did consider if SPAID would survive and in her private correspondence she informed Ted Beckett and Lord Avebury that if it were not for their support and advice she would have had to give up on SPAID. Nancy Tait, in attempting to keep SPAID relevant was also prepared to slightly exaggerate its size. In one press release a certain Laurie Kazan-Allen was described as the SPAID Press Officer, perhaps without her knowledge! However, supported by her allies Nancy persevered and by 2007 had handled over 3,000 cases, providing not only tremendous support to the victims of asbestos and their families but gaining greater recognition of the hazards of asbestos. Some cases Nancy fought lasted more than ten years and she would often travel from her home in Enfield to elsewhere in the UK to attend a hearing, argue the case on behalf of a victim or publicise the dangers of asbestos.

Nancy also collected a massive amount of information on asbestos and its victims to which anyone who uses the OEDA archive can testify. She used this to aid an extensive list of contacts, often writing to provide advice to US lawyers or those involved in setting up fledgling victims' support groups elsewhere whether it be in Hull or Los Angeles. She corresponded with Michael O'Connor, the Vice-President of

Chase-Manhattan Bank who was involved in a legal battle with T & N in New York and she used this information to fight for asbestos victims in the UK. In her later years, Nancy continued campaigning and OEDA opened its final case in 2007 when she was 88 years old. By then Nancy had been vindicated. Even then she was prepared to use this to fight for victims. For example, when she was awarded an honorary doctorate she began using the prefix Doctor when contacting the Industrial Injuries Advisory Council (IIAC) and challenging medical opinions and experts. Even with asbestos imports banned and a stronger network of campaign organisations as she had predicted much earlier, her capacity for campaigning did not diminish though age did slow her ability to fight on as many fronts as previously. Nevertheless, she recognised that many more victims of asbestos and their families would suffer and her environmental influence still led her to believe that asbestos in place continued to present a great danger. Her legacy is one of recognising a great wrong and having the determination to do something about it with nothing other than a razor sharp mind and a willingness to help others. It was a recognition that complacency and a failure to be vigilant would lead to more unnecessary and needless deaths and someone had to act to change this. Nancy never ceased campaigning for victims and never gave up on the pursuit of justice.



Nancy Tait



William Ashton Tait

## ASBESTOS VICTIMS AND THE ONGOING FIGHT FOR JUSTICE

Graham Dring, Chair of the Asbestos Victims Support Groups Forum UK

Ten years have now passed since campaigners first established the Asbestos Victims Support Groups Forum UK (the Forum) with the aim of providing a unified campaigning voice for asbestos victims. Our members help thousands of people each year to secure the welfare benefits and government lump sums they are entitled to. But it is vital that we do more than just ameliorate the financial consequences for individuals who develop asbestos diseases, as important as that job is. We need to campaign and fight for justice for all asbestos victims.

Asbestos victims were knowingly and negligently betrayed by employers who put profits before the lives of workers and their families, and by successive governments who dragged their feet by not banning the use of asbestos in the UK until 1999, decades after the dangers were clearly identified. To add insult to injury, since asbestos diseases generally develop decades after exposure, victims have often died uncompensated because employers have gone out of business and insurers could not be traced.

The insurance industry has also launched a series of court cases (Fairchild, Barker, Trigger), seeking to limit compensation for mesothelioma victims, attempting to profit from the long latency period between exposure and development of the disease. It seems it was not enough that many victims should die uncompensated because of the negligent (to be charitable) failure of insurers to maintain proper records. Those victims who were able to trace a liable insurer would now have to deal with an ever changing obstacle course set by insurers attempting to deny justice to people with only months left to live.

In the 2002 Fairchild case, insurers argued that where a mesothelioma victim had been exposed to asbestos by more than one employer nobody could be held liable as it could not be proved which exposure had caused the onset of mesothelioma. In the later Trigger case, they claimed that the wording of policies meant that the date of onset of the disease, rather than the date of exposure, should be the “trigger” for an insurer’s liability. The envisaged denial of liability relating to the time of exposure would have left many mesothelioma victims without compensation, since no redress could be sought from employers who had ceased trading by the time an employee’s disease was diagnosed. In the 2006 Barker case, insurers ran the argument that where there had been more than one negligent employer, each employer should only be liable for compensation proportionate to the extent of their exposure.

The Forum led campaigns against all these attempts by insurers to wriggle out of their responsibilities. At the heart of these campaigns were victims and family members directly affected, who stood up to the insurers with dignity and determination. They lobbied MPs, wrote to newspapers, spoke on TV and radio and protested outside the courts. The insurers failed in most of their attempts to deny victims justice. Their judicial success in the Barker case was overturned by the introduction of the Compensation Act by the then Labour government.



Forum chair Tony Whitston presenting letter to Nick Starling of the Association of British Insurers, 2009

More recent attempts to deny justice for victims have come via Parliament. The Legal Aid Sentencing and Prosecution of Offenders Act 2012 (LASPO 2012) contained a clause that cut civil compensation awards in personal injury cases. The Forum led a successful campaign to exempt mesothelioma victims from the effects of this clause. Lord Alton moved the motion in the House of Lords that was eventually accepted by the government. When the government tried to lift the exemption in 2014, the Forum won a judicial review and this attempt was overturned by the High Court.

In 2013, the Ministry of Justice launched a consultation on reforming mesothelioma civil compensation claims. The proposals contained, amongst other things, a pre-action protocol drawn up by the Association of British Insurers (ABI), hardly an impartial player, which would have led inevitably to further obstacles in securing timely justice for mesothelioma victims. It was clear that the insurers had the ear of government (subsequent revelations confirmed secret meetings and promises made); however, the Forum obtained a judicial review challenging what we felt was a flawed and biased consultation process. The

government subsequently dropped most of the proposals before the judicial review could be heard.

One of the greatest injustices faced by asbestos victims has been the lack of a mechanism for securing compensation when negligent employers have gone out of business. The insurance industry systematically destroyed records, leaving many victims unable to trace or prove which insurer was on cover at the time they were exposed to asbestos. The Forum campaigned hard for the establishment of a fund of last resort, funded by insurers, to compensate asbestos victims unable to trace a negligent employer or insurer to sue. In 2010 the Labour government launched a consultation and in 2014, under the Coalition government, the Mesothelioma Act was finally passed, setting up the Diffuse Mesothelioma Payments Scheme (DMPS), applicable from April 2014.

Compensation from the DMPS is only payable to mesothelioma victims diagnosed after 25 July 2012 and initially was set at 70% of the average figure awarded in court claims. The Forum's "100% Justice" campaign argued for compensation to be awarded at 100% of average court awards, for the cut-off date to be 10 February 2010 (when the consultation was first announced) and for other asbestos diseases to be included under the scheme. Forum briefings were sent to every member of the House of Lords and House of Commons; victims and family members wrote to their MPs. The government conceded partially and increased compensation to 80% before the passing of the Act (this was subsequently increased to 100% from February 2015). The introduction of the DMPS is, of course, welcome as some mesothelioma victims will receive compensation previously denied to them. But the Forum continue to campaign for further improvements, including compensation for victims of asbestos-related lung cancer, asbestosis and pleural thickening.

### **So what does the future hold?**

There is no getting away from the fact that the 2015 General Election result makes it harder to secure the reforms needed to secure justice for asbestos victims. Already the government has announced that they intend to review the LASPO mesothelioma exemption at some point over the next two years. No doubt there will be more challenges to come.

In 2015, the Forum published its Charter for Justice, which contained a number of easily affordable reforms that would secure improvements for those living with asbestos diseases and their families.

Mesothelioma research will be at the heart of Forum campaigning over the coming months and years. Government funding for mesothelioma is pitifully small. We need to be able to give sufferers hope for the future that improvements in treatment and a cure can be found. That means government committing

funding for research. No more excuses, no more delays.

We will continue to campaign for improved compensation for all asbestos victims. The government must ensure the Diffuse Mesothelioma Payments Scheme is properly funded through a minimum 3% levy on relevant insurers, the figure insurers claimed they could afford without passing on costs to customers and the figure the government said would be set during debate on the Mesothelioma Bill in Parliament. The DMPS started its life as a cut-price scheme because of the failure to impose an adequate levy on insurers. We need proper funding to guarantee 100% compensation for all future mesothelioma applicants and to compensate victims of other asbestos diseases, who face the same difficulty in tracing former employers or their insurers.

We will seek ways to work more closely with asbestos victims' support groups in other countries and build on the ties which have been developed in recent years via attendance at pivotal meetings and events in Europe. On 17 & 18 September 2012, Forum members Doug Jewell and Joanne Carlin (now Gordon) participated in a Brussels Conference entitled *Europe's Asbestos Catastrophe: Supporting Victims, Preventing Future Tragedy* along with representatives of asbestos victims' groups and trade unions from several EU countries; delegates at a workshop during this event began discussions on the formulation of a European Charter for Asbestos Victims. On 18 September, conference delegates attended an asbestos hearing convened by the European Parliament's Committee on Employment and Social Affairs.

In November 2014, the Forum sent a delegation of 13 members from Birmingham, Manchester, Derbyshire and Liverpool to Italy to show solidarity with asbestos victims whose landmark case against the giant Eternit asbestos conglomerate was due to come to fruition after more than a decade of litigation. On 18 November, Forum members stood shoulder to shoulder with scores of European asbestos victims, campaigners and Italian victims at the Court of Cassation, Italy's Supreme Court, to hear the verdict against asbestos billionaire Stephen Schmidheiny who had been tried on charges relating to the asbestos deaths of thousands of Italian workers and citizens. In the aftermath of the Court's disastrous ruling – the case was thrown out on a technicality – the delegation travelled to Casale Monferrato, the town at the centre of Italy's asbestos epidemic, to show support for those affected and their relatives and take part in discussions, a press conference and a torchlight demonstration.

On 24 June 2015, Forum member John Flanagan from the Merseyside Asbestos Victims Support Group addressed European Union officials and delegates at an EU conference entitled "Freeing Europe



John Flanagan presenting evidence on behalf of the Forum at EU asbestos hearing, 2015

Safely from Asbestos.” John’s presentation highlighted the work of the Forum and the ongoing needs of asbestos victims. Having issued a call for positive action on a wide range of issues, including the need for adequate funding for mesothelioma research and support for the injured, a ban on the transshipment of asbestos through EU ports and the imposition of mandatory asbestos surveys of the built environment, John showed an extract from a video of the late Andrew Burns, a mesothelioma sufferer who died in his late thirties, having been exposed to asbestos whilst employed on UK industrial sites.

Recognising the multinational dimension of the asbestos epidemic, the Forum must continue to develop links with like-minded organisations and individuals

in Europe and beyond. It beggars belief that asbestos is still being mined and sent to countries in the developing world, despite all we have learned about its effects in this country. We must step up the campaign for a worldwide ban and expose the lies of the asbestos industry and the scientists they have bought and paid for.

And we should remember all those who have lost their lives to asbestos and honour their memory by fighting for justice with, and for, the loved ones left behind, those living with mesothelioma and other asbestos diseases now, and those to come in the future. This is a fight for justice, not sympathy – the betrayals of the past will galvanise us to secure justice now and in the future.



Forum members in ban asbestos demonstration at Russian Embassy, London 2013

# TWENTY YEARS OF LEGAL CHANGES IN SCOTLAND

Phyllis Craig MBE, Manager/Senior Welfare Rights Officer of Clydeside Action on Asbestos

The last 20 years have brought significant changes to the rights of asbestos victims in Scotland. Devolution created a Parliament ready and willing to act in the interests of the victims of what is recognised and accepted as a shameful legacy of the country's otherwise proud industrial heritage. What has been most encouraging is that support has been, for the most part, irrespective of party politics. The asbestos campaign groups have been relentless in their efforts and have achieved remarkable success in bettering access to justice in the Scottish Legal System. This has had an impact on those with an asbestos related disease (ARD), both with regard to civil damages and legislation affecting benefit entitlement.

## Legislation/Civil Compensation

### The Court Process

In 2003 there was substantial reform of the Rules of The Court of Session, the court in which the majority of mesothelioma cases are heard. This provided an opportunity for campaigners to seek a fast-track procedure for mesothelioma cases. That procedure was implemented, and a mesothelioma case can now be heard within weeks of entering the court process.

### Courts Reform (Scotland) Bill

Phyllis Craig MBE, Chair of Clydeside Action on Asbestos (CAA), gave evidence on 22 April 2014 to the Justice Committee of the Scottish Parliament regarding CAA's opposition to some of the proposed reforms contained within the Courts Reform (Scotland) Bill.

The proposed Bill sought, amongst other reforms, to remove all asbestos cases, where the value was deemed to be less than £150,000, from the Court of Session to Sheriff Courts. Advocate fees would not be recoverable under the proposed changes.

Clydeside Action on Asbestos and its members attended the outcome of the vote concerning the Courts Reform Scotland Bill whereby MSPs voted by 81 votes to 31 to defeat proposed amendments which sought to ensure that all asbestos-related injury cases would continue to be heard at the Court of Session.

CAA had many members present in the Parliament; some had lost their partner or a family member to an asbestos-related disease, some were suffering from mesothelioma. When the vote came, they reacted with anger and incredulity. They voted with their feet, voicing their disgust towards the chamber, prompting the Presiding Officer to temporarily suspend proceedings. Amidst the anger there was also

an unspoken sense of pride and determination. As well as fighting illness, many, perhaps for the first time, realised they would also have to fight for justice.

### Evening Times 8.10.2015

"Asbestos victims react with fury to court claim changes"

(See: [http://www.eveningtimes.co.uk/news/13293456.Asbestos\\_victims\\_react\\_with\\_fury\\_to\\_court\\_claim\\_changes/](http://www.eveningtimes.co.uk/news/13293456.Asbestos_victims_react_with_fury_to_court_claim_changes/))

### Daily Record: 6 November 2014

"Terminally ill grandad tackles MSPs over refusal to offer more support to asbestos victims"

(See: <http://www.dailyrecord.co.uk/news/scottish-news/terminally-ill-grandad-tackles-msps-4572874>)

It was felt by many to be a betrayal. In the long tradition of campaigning on asbestos issues, some put the cause before themselves. Charlie Bridgewater, member of CAA, personified this. Charlie, who was dying from mesothelioma, gave an interview to the Daily Record/Sunday Mail on his feelings following MSPs voting down the proposed amendment to the Courts Reform Bill which would have protected sufferers from higher legal costs.

Charlie, a father of two and grandfather of four, said:

"I am not a naive person but it really opened my eyes to the cynical way in which the Parliament operates."

The selfless campaigning of people like Charlie gives us all strength and reinforces our own determination to carry on our work in seeking recognition and justice for all victims.

(See: <http://www.clydesideactiononasbestos.org.uk/news/caa-reaction-to-scottish-parliament-vote-on-court-reform-bill>)

### Mesothelioma Claims

Those advising mesothelioma victims are all too familiar with the terrible discussion which has to take place as to whether to try to settle their legal claim in life, and by doing so forgo any claims that their widow or family might make, or to wait until after their death to ensure those claims are protected. In Scotland, recognising the intolerable pressure this puts victims under, the Parliament responded to campaigning and passed the rights of relatives to Damages (Mesothelioma) (Scotland) Act 2007 which effectively removes the need for that invidious discussion. A mesothelioma victim can settle his or her claim in life and this will have no detrimental effect

on the subsequent rights of their loved ones to make further claims.

Those that are unable to pursue civil compensation because they are unable to trace a relevant liable party can now pursue a payment under the Diffuse Mesothelioma Payment scheme [DMPS] 2014.

### Family Claims

Unlike in England and Wales, family members of those who have died of an asbestos related condition are entitled to “bereavement” awards of compensation in Scotland. These claims were previously restricted to the parents, spouse, children and, somewhat oddly, the children-in-law of the deceased. The Family Law (Scotland) Act 2006 extended these awards to the siblings and grandchildren of victims and also clarified the position in respect of step children and grandchildren.

### Pleural Plaques

The successful campaign to re-establish the right of sufferers of pleural plaques in Scotland to pursue compensation, resulting in the introduction of the **Damages (Asbestos-related Conditions) (Scotland) Act 2009**, was a landmark victory. The campaign organised by CAA, with the support of all the Scottish asbestos groups and Thompsons solicitors, in particular, the late Frank Maguire, received overwhelming support from civic Scotland. This included trade unions, MSPs, MPs, healthcare professionals, local councillors and personal injury solicitors. The Act was not supported unanimously by all parties in the Scottish parliament with the Conservatives voting against the bill. Political support for asbestos-related legislation is not certain and can never be taken for granted.

Not surprisingly, the insurance industry sought to have the legislation revoked on the grounds of constitutional incompetency. Despite pushing it all the way to the Supreme Court, that attempt failed and pleural plaques cases have been progressing in Scotland since 2011. Recent court decisions have begun to push up the value of these claims which is another welcome step towards justice. Despite success with the pleural plaque legislation, difficulties continue to arise in relation to “time barring” particularly in plaque cases: *Aitchison v Glasgow city council*.

### Damages (Scotland) Act 2011

Following the political momentum during the introduction of the pleural plaque legislation there was another major positive change for asbestos sufferers and their families. The **Damages (Scotland) Act 2011** ended the lengthy legal wrangling over damages claims. The Bill, introduced by Bill Butler MSP, improved the rights to damages in respect of personal injuries and wrongful death.

CAA was present at the Scottish Parliament to see the Bill being passed unanimously by MSPs from all

parties. The Damages (Scotland) Act overhauled the previous system and provided a fair level of compensation in cases of wrongful death, without the need for unnecessarily long and distressing court cases. The changes benefit hundreds of people across Scotland each year.

This Act was again supported by all the asbestos groups and sought to simplify and clarify the way that financial losses are calculated in cases where someone has died from an asbestos related condition. The overall result has been higher financial settlements both for victims and their dependent relatives, as well as a far less drawn out and controversial process for calculating the losses.

The late Frank Maguire of Thompsons Solicitors, who helped draft the Act, explained the practical impact the new Act would have on victims and their loved ones:

*“It sweeps away what has, up till now, been the law’s anachronistic and sexist view of society, based on an outdated stereotype of the man as the breadwinner and the woman as the housewife. The new legislation also means families will no longer have details of their income and expenditure scrutinised and argued over in court in their darkest hour.”*



Frank Maguire

(See: <http://www.clydesideactiononasbestos.org.uk/about-caa/campaigns>)

### Going Forward

#### The Recovery of Medical Costs for Asbestos Diseases (Scotland) Bill

A new bill designed to recover the medical costs of investigating and treating people suffering from asbestos related disease was launched by Clydeside

Action on Asbestos (CAA) and Scottish Nationalist MSP Stuart McMillan in January 2015.

Clydeside Action on Asbestos estimate that over £20 million pounds per annum is spent by NHS Scotland in diagnosing and treating people suffering from the effects of asbestos exposure. This bill will enable the NHS to recover costs from insurance companies who have already settled civil claims. The costs of treatment will be calculated from a patient's initial diagnosis. Therefore given that the infrastructure already exists for accident cases it is anticipated that the introduction of the bill could be straightforward. It is envisaged that there will be strong resistance by the ABI to the bill.

(See: <http://www.clydesideactiononasbestos.org.uk/about-caa/campaigns>)

### IIDB and Devolution

Following the "no" vote in the Scottish referendum, Lord Smith of Kelvin was appointed by the Prime Minister to take forward proposals on further powers for the Scottish Parliament. The Smith Commission reported with its recommendations on 27 November 2014.

On welfare, the Commission proposed that a range of disability benefits, including Industrial Injuries Disablement Benefit (IIDB), should be devolved. The Scottish Parliament would have complete autonomy over these benefits.

There are currently 32,200 people in Scotland in receipt of IIDB with an estimated spend in 2013/14 of £91 million.

Between 2003 and 2013, 4,015 Scots were awarded IIDB for an asbestos-related prescribed industrial disease; 1,670 were suffering from mesothelioma (150 of whom were female) [1]

There are additional benefits being devolved to the Scottish Parliament; however, it remains to be seen what impact this will have on those with an ARD.

### Conclusion

People continue to die in their thousands due to the negligence of others, whether on an individual or corporate basis. The disgrace of employers' historical widespread disregard for an individual's health and

safety has ever so slowly led to an increase in legislation and enforcement, which has resulted, in some employers being given custodial sentences. Employers/insurers still have questions to answer in terms of their conduct and attitude towards the victims of the asbestos tragedy.

A look at today's headlines, or a quick entry of the word asbestos into any search engine, quickly informs us that there is still much that needs to be done. However, there have been changes and improvements in the landscape of benefits and compensation over the last two decades which have had a positive impact. While not all are monumental changes, they nonetheless make a real and tangible difference to people's lives.

We are aware that the Scottish system is not perfect. More court reform this year has raised the spectre of additional costs to claimants if they are to meet the insurers on an equal footing in Court. The erosion of health and safety law on both sides of the border can spell nothing but bad news for all those who are injured in their workplace, be it through accident or industrial disease. However, in Scotland we have reaped the benefits of determined and unified campaigning and lobbying of a Parliament broadly minded to listen to the concerns of asbestos victims. CAA will continue to fight injustices placed on those with an asbestos condition. However, constant vigilance is required to combat the efforts of the insurance industry to avoid what is due to victims and to put obstacles in the way of accessing justice.

CAA would like to dedicate this paper to the late Frank Maguire of Thompsons Solicitors, who was instrumental in all of the legislative changes within the Scottish Parliament in respect of those with an asbestos condition.

### Reference

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Launch of CAA toolkit, 3 December 2015 in Scottish Parliament

## ASBESTOS IN SCHOOLS – A FIFTY YEAR SCANDAL

Michael Lees MBE, Founder Member of the Asbestos in Schools Group

There is a major problem of asbestos in schools in Britain. It is a scandal that remains unresolved after fifty years

More than 85% of schools contain asbestos [1]; much of it in the most dangerous types of asbestos materials, where toxic fibres are readily released as the materials degrade over time or are damaged. In many locations such materials are vulnerable to damage by children and staff. As a consequence, teachers, support staff and former pupils are dying of mesothelioma, the deadly cancer almost always attributable to the inhalation of asbestos fibres.

Government data, obtained through a series of freedom of information requests, showed that 308 school teachers had died of mesothelioma since 1980, of which 155 had died between 2003 and 2013 [2]. But they are the tip of the iceberg, as it is estimated that between two and three hundred people will die each year due to asbestos exposure experienced *as children* at school during the 1960s and 1970s [3].

The asbestos containing materials (ACMs) were incorporated when the schools were built or refurbished, but because of government policy most of the asbestos used in their construction remains in place. Over the last fifty years officials have advised the government that, despite the pervasive presence of asbestos, there was a negligible risk to staff and pupils. Even when it was clear this was not the case. The scale of continuing risk was played down; if asbestos materials were “managed” any slight risk that there might have been before would be eliminated – or so claimed government officials responsible for the safety of our children. And, for a variety of reasons, they have maintained this policy of managing asbestos while advising against removing it.

The main agency tasked with devising asbestos policy, including that for public buildings such as schools, is the Health and Safety Executive (HSE). The cornerstone of its current advice for buildings is “Asbestos which is in good condition and unlikely to be disturbed or damaged is better left in place and managed until the end of the life of the building as this presents less risk of exposure to the occupants than the process of removing it” [4]. The critical flaw in this contention when applied to schools is that they differ from most other premises in one important respect – they contain children, a lot of children. They are boisterous places where children will inevitably disturb and damage asbestos materials if they are accessible to them, when adults would not.

As for asbestos removal, more than twenty years ago (1993) the HSE itself privately acknowledged that

asbestos can be safely removed and that, because of the presence of children, systems of asbestos management can fail in a school [5]. Things have advanced even further since then. It is now generally accepted that, using approved methodologies, asbestos can be removed without danger to the public. Indeed, phased removal is now the preferred option in many commercial organisations (and in the Houses of Parliament [6]). Application of such a radical policy for schools, though costly, would remove forever the risk of asbestos exposure in classrooms.

It is a reasonable assumption that the rationale behind the government’s policy for schools is that although the effective management of asbestos entails a continual and expensive drain on financial resources, the expense is spread over the life of the building, whereas removal would entail a significant cost over a short period of time. As most schools contain asbestos the immediate cost to central government funds would be considerable.

The Asbestos in Schools Group proposed the phased removal of asbestos from schools. Priority being given to those schools containing the most dangerous asbestos. In the interim there has to be a rigorous system of asbestos management. In the 1980s this was the policy of the Association of Metropolitan Authorities. They reasoned that phased removal is safer and, in the long run, it is also cheaper [7]. The practice stopped when the organisation ceased to exist, however phased removal remains the policy of Nottinghamshire. It also has been adopted as Government policy in Australia, incorporated in the 2013 Asbestos Safety and Eradication Bill [8].

But why was so much asbestos used in school construction in the first place, when there was evidence of the dangers of exposure to it? And what lies behind the reluctance to remove it? The answers to these questions are complex and interlinked. But the reason so much asbestos was used stems, in part, from the adoption of a particular building style in Britain during several decades of the mid-twentieth century.

Following the end of the Second World War, the government and the Department of Education and Science was confronted with the need to build a great number of new schools and replace or refurbish many more. Consequently, there followed a school building boom, with more than fourteen thousand schools being built between 1945 and 1975. The peak year was 1968, when more than six hundred schools were constructed [9]. To meet the demand, industrialised “System” built principles were intro-

duced, where dimensions were standardised and components prefabricated in factories. At that time the use of asbestos was at its height, so asbestos materials were used in school construction and refurbishment [10]. But for System built schools, in particular, the preferred designs specified the incorporation of *large quantities* of these materials.

System (school) buildings were normally based around a frame made of steel, concrete, wood or aluminium on which was placed external and internal cladding. The light structure used in most of the designs is vulnerable to fire damage and therefore extensive use was made of asbestos materials [11]. Materials containing chrysotile (white asbestos) were extensively used, but so were the amphiboles, with, in particular, large quantities of amosite (brown asbestos) and to a lesser extent crocidolite (blue asbestos). The amphiboles were incorporated in the form of sprayed asbestos, lagging, and asbestos insulating board (AIB). Chrysotile can cause mesothelioma but amosite is up to 100 times more likely to and crocidolite up to 500 times [12]. Of greatest concern is the presence of these lethal materials in locations accessible to children: AIB panels in ceilings, walls, window reveals, door surrounds, heaters, fire-doors in classrooms, halls, gyms, corridors, cupboards and toilets. All of these are vulnerable to damage and will easily release (mainly amosite) asbestos fibres if disturbed.

It should not be thought from the foregoing that the widespread use of asbestos in school construction was excusable, a result of ignorance about the risks involved; on the contrary, by 1965 (at the height of the school building boom) there was increasing awareness of the dangers of asbestos, as evidenced by the annual report of the Chief Inspector of Factories who highlighted the fact that mesothelioma had been shown to be associated with exposures to asbestos "Sometimes of astonishingly slight degree" [13]. Aware of the widespread use of asbestos in classrooms, the Department of Education sought the advice of the Chief Medical Officer of the Factories Inspectorate who warned of the dangers of asbestos, and advised against the use of asbestos in schools, stressing that children were particularly vulnerable to exposure. While admitting that the science was not complete, he concluded: "The important point to me is that you are dealing with children... The more I see of asbestos, the more I dislike it" [14].

Regrettably, such warnings were not heeded; the building program proceeded apace (still using asbestos materials) and school personnel and the public were not given the full facts about the scale of the problem or the potential risks. Though, in 1967, a warning was issued to all schools [15], under pressure from the asbestos industry, it was watered down. Cape Asbestos and Turner and Newall's overriding concern was the likely damage to their industry if people thought that asbestos in buildings could harm

their health. They consequently wrote to the Secretary of State for Education claiming, incorrectly and contrary to the growing evidence [16], that "Their anxiety is based on an unjustifiable exaggeration of the health hazards...there is no evidence whatsoever that the incorporation of asbestos in buildings has ever impaired the health of the occupants" [17]. They went further in ensuring that the concerns of teachers were quelled by repeating their incorrect claims in the Times Education Supplement. The Board of Trade gave its support to the asbestos industry and was pleased that the policy of "quiet reassurance" had "headed off secondary alarm" [18].

Most controversially of all, the Department of Education Architects and Building Branch gave support to the flawed claims of the asbestos industry [19]. One Department of Education official protested that the department was taking a different line from the one advised by the principle experts in the country, but his protests were in vain [20]. The warnings had been given by experts and yet they were ignored; instead, the department allowed the continued use of asbestos materials in classrooms and knowingly oversaw the design and construction of thousands of schools where the extensive use of asbestos materials was specified.

About half the schools in the country are System built [21] and many of them were constructed by consortia of local authorities, the first being CLASP (Consortium of Local Authorities Special Programme) established in 1957. However, the Architects and Building Branch had overall control of the building program and was responsible for the design and development of new schools.

It is significant that, to better achieve ambitious building targets set by government, many senior officials in the branch were pioneers of System building, recruited from local authority consortia, and having strong commitments to the use of asbestos materials. For example, in 1964 the Chief Architect of CLASP moved to the Architects and Building Branch as Chief Architect, where he later became head of the branch, remaining until 1975 [22]. Since he had been at the fore in the development of System built schools, it is not unreasonable to assume that the Architects and Building Branch's denial in 1967 that asbestos in schools could harm the occupants stemmed in a large part from the fact that the branch's chief architect, together with like-minded branch officials with similar backgrounds, specified and encouraged the widespread use of asbestos materials in school construction.

The use of amphiboles rapidly slowed in the late 1970s, until their import and manufacture were finally banned by law in 1985 [23]. But the damage had already been done; by then the vast majority of schools in the country contained asbestos, with most System built schools containing large amounts of

amosite. Britain imported more amosite than any other country and this is considered the reason we have an exceptionally high incidence of mesothelioma [24].

In 1979 the government's Advisory Committee on Asbestos again highlighted the greater risks that children faced from asbestos exposure, compared to adults [25], but the US authorities had gone a step further. Following an audit of the extent of friable asbestos in their schools, they estimated that for every teacher and support staff death from mesothelioma, nine former pupils would die from their asbestos exposure at school. As a result, in 1986 stringent laws were introduced in the US specifically for schools; it being acknowledged that, because of the increased vulnerability of children, schools had to be treated as special places (with regard to asbestos regulations). In contrast to UK practices, the US advocated a policy of openness [26].

In Britain, to this day no such audit has been carried out to determine the extent of asbestos in schools and no official estimate has been made of the number of people who are likely to die as a result of their asbestos exposure at school. Some fourteen years after the US action, calls for an audit in the UK were turned down because: "Commissioning a nationwide survey might provoke unnecessary panic" [27].

A comprehensive audit of the condition of school buildings in England was completed in 2015, but an assessment of the extent, type and condition of asbestos materials was specifically excluded [28]. This decision was taken despite the presence of asbestos being one of the most expensive items when school buildings are maintained, refurbished or demolished; excluding assessment of such costs means that any future financial forecasts will be meaningless. (This course of action appeared to be a politically motivated; without embarrassing data, there would be no pressure to produce a proportionate or proper response – and the public would remain unaware of the scale of the problem.)

In 1997, consultations took place regarding the Control of Asbestos Regulations. Since it was proposed to make the management of asbestos mandatory, it was proposed that asbestos surveys also be made compulsory. The Building Research Establishment and the Department for Health supported the proposal. However, the Department for Education argued strongly and successfully against asbestos surveys being made compulsory, their reasons being revealed in a letter:

"Like you we are not very keen on the idea of surveying all the schools. The cost of the surveys, removal and reinstatement would be prohibitive... We also feel that it would not be fair to single out schools for such survey thus implying that they are more at risk." [29]

This letter was written to the HSE by the head of the Department for Education Architects and Building Branch the senior official responsible for school buildings and advising ministers on government policy. He joined the department in 1982 and was head of the branch from 1997 to 2008 [30]. He ignored the expert opinion of the Building Research Establishment, the Department of the Environment and the Medical Research Council [31]. The fact that he argued against schools identifying their asbestos is appalling, and has inevitably led to the continuance of unsafe practices in many schools. As a senior official with a duty of care for every child in the country, his dismissal of the particular vulnerability of children to asbestos exposure in schools provided the government with a further excuse for inaction.

While arbitrarily denying that there *was* a particular risk from asbestos in schools, in 1997 the Department for Education also advised the schools minister against assessing the scale of any such risk. An internal background ministerial briefing gave the reason why:

"A central government initiative to assess the risks to teachers and pupils would not only be inappropriate, given where the statutory responsibility lies, but would also lead to pressure for centrally funded initiatives to remove all asbestos and for other aspects of building work. That would be extremely expensive, as well as risky and disruptive for the schools concerned." [32]

With no official assessment of the extent of asbestos in schools or of the risks involved, the HSE and the Department for Education could publicly deny that there was any problem with asbestos in schools – officially there wasn't.

In contrast to the above, in the same year, a report by the Medical Research Council and the Building Research Establishment had concluded "It is not unreasonable to assume, therefore, that the entire school population has been exposed to asbestos in school buildings." It highlighted the particular risks in System built schools, assessed lifetime asbestos exposures and estimated that "Children attending schools built prior to 1975 are likely to inhale around 3,000,000 respirable asbestos fibres... Exposure to asbestos in school may therefore constitute a significant part of total exposure" [33]. The above exposure estimate was based on asbestos being in good condition but it was stressed that fibre levels are a lot higher when asbestos is disturbed or damaged. Consequently, the numbers of fibres released and inhaled can be significantly greater than in this estimate, and there is considerable evidence of frequent disturbance and damage in schools [34]. But the warnings sounded in the above report were evidently unheeded by officials steering Department for Education and HSE policies on asbestos.

The inevitable consequence of large quantities of friable asbestos materials accessible to children in schools is that asbestos fibres are released. In 1987, air tests carried out in a System built school in London showed that when a door was slammed or when a wall was hit large numbers of asbestos fibres were released into rooms. In one test, a concentration of 330,000 (mainly amosite) fibres per cubic metre of air was detected after slamming a door just five times [35]. Despite the serious nature of these findings and the widespread implications, there is no evidence that the public was alerted or that a warning was issued to the many thousands of other schools that contained asbestos insulating boards in similar locations vulnerable to damage by children.

It was only when the problem was rediscovered twenty years later in 2006, when tests were carried out in a number of CLASP schools, that measures were taken to inhibit the release of asbestos fibres in thousands of System built schools. The tests showed that hitting a wall or column, slamming a door or even sitting on a window sill could release (mainly amosite) fibres – amounting to as much as 420,000 fibres per cubic metre – into classrooms. Presumably, fibres had been repeatedly released by such activities since the schools were built more than forty years before. However, the HSE advice was not to remove debris or damaged, deteriorating asbestos, but instead to “manage” the (asbestos) problem by applying silicone sealant to every crack and gap. This was bad, unsafe advice and such seals have been shown to fail. But for administrators such “containment” was an easy solution to their asbestos problems; enabling reassurances to be given that staff and children were safe – the asbestos was being “managed.” It was an approach that also avoided the considerably greater expense of removing the asbestos or demolishing the school [36].

In 2004, the HSE introduced two initiatives; the first, an extraordinary, retrograde measure denying information about asbestos incidents occurring in a school to concerned parents. Against their own expert medical advice [37], the HSE decided that parents need not be informed of their children’s asbestos exposure at school unless it exceeded the Action level [38]. This is a dangerous level of exposure for adults, let alone children. It is meant to be applied to contractors working on asbestos – who have to wear protective clothing and breathing apparatus. As a consequence, asbestos incidents have occurred in schools without being officially recorded, and parents and children have not been informed they have taken place. The Asbestos in Schools Group argued successfully for this flawed guidance to be withdrawn and it finally was in 2012 [39].

The second HSE initiative was introduced following some *acknowledged* serious asbestos incidents. It was a campaign to improve asbestos management in schools and “to reduce exposure dramatically over

the next few years” [40]. A year later the campaign was dropped before the first meeting had taken place, so that resources could be reallocated to achieving Public Service Agreement targets of reducing asbestos exposure for building maintenance workers [41].

The Department for Education was asked to take over the campaign, but they declined, not being willing to accept that they had overall responsibility for the safety of staff and pupils. It was not until 2010 that the campaign was re-established following a meeting between the Asbestos in Schools Group and the Prime Minister. The department finally accepted that it had overall responsibility and established the Asbestos Steering Group to improve asbestos management in schools. This was a major step forward, and since then this group has made some significant improvements. But government policy remained reliant on advice from the HSE.

In 2009, the HSE Director of the Disease Reduction Programme issued the following unsubstantiated (and incorrect) reassurances: “Even if asbestos dust was released from floor tiles, ceiling tiles, wall panels and other common materials and was inhaled by teachers and pupils, the doses would be too low to cause any problems...” [42] and “There is also no evidence to suggest asbestos can affect children more than adults” [43]. These statements were not only contrary to expert opinion and the evidence, but the fact that such views were expressed by a senior official who advised ministers on asbestos policy, makes it little wonder that effective action on asbestos in schools has not been taken.

Clearly, the unambiguous statements made some fifty years before – that children were more at risk from exposure to asbestos than adults – had once again been conveniently put to one side. This led the Asbestos in Schools Group to propose that a new assessment of this particular risk should be made. The suggestion was taken up, and in 2013 the government’s advisory committee on cancer, the Committee on Carcinogenicity (CoC), completed a two year study which confirmed children were indeed more vulnerable to asbestos exposure than adults. The younger the child the greater the risk: the lifetime risk of developing mesothelioma for a five year old child is 5.3 times greater than that for an adult aged thirty. The fact that children were more at risk should have formed the basis for all asbestos policy for schools. But it has not. If the mistakes of the past are not to be repeated it is essential that a realization of this vulnerability underlies all future asbestos policy for schools.

While it had been made clear that schools were expected to manage their asbestos themselves, in 2011 the HSE decided they would not even carry out proactive inspections of local authority schools to assess whether they were managing it safely [44]. After all, they had officially advised the government that schools were “low risk” [45]. This policy was later

extended to all schools and remains government policy.

At the Education Select Committee hearing on Asbestos in Schools in 2013, a senior HSE official stoutly expounded HSE policies and assured MPs that these policies were working: staff and pupils were safe. Even though the HSE Chief Executive at the time has, since leaving the organisation, questioned key elements of those policies and advocated measures diametrically opposed to them [46], government policy continues to be based on the official HSE line – however flawed the reasoning supporting it.

In 2013, I accompanied a nursery school teacher, who was suffering from mesothelioma, to a meeting with the schools minister. The teacher very eloquently and bravely explained to the minister how government policies had failed to ensure that children and staff in schools were safe. She provided evidence that present government policies were not working, and said that fundamental changes needed to be made.

The minister assured her that if there was evidence that asbestos posed a risk to school staff and pupils then, regardless of cost, measures would be taken to ensure that schools were made safe. However, he stressed his policy was based on HSE advice, and this advice was that staff and children were not at risk from asbestos in schools. Furthermore, it was the HSE's view that, in general, school authorities were effectively managing their asbestos. Therefore, on the evidence available to him, he could not justify to the Treasury the need to spend large amounts of money on mitigating the effects of asbestos in schools [47].

In 2015, the government published a policy review on asbestos in schools. This was a step forward and a number of improvements were proposed. However, the review again stressed that policy was based on HSE advice; seemingly an excuse to essentially maintain the status quo. It appeared the opportunity to establish a long term strategy or make the fundamental changes required to make schools safe had been missed.

There are, however, glimmers of hope; the current Department for Education official with responsibility for school buildings (recruited from the commercial world) *acknowledges* that there is a problem and that measures have to be taken to solve it. The policy review did accept that staff and pupils had been exposed to asbestos at school and that former pupils and staff were dying of mesothelioma. A questionnaire has been subsequently issued by the Department for Education to all schools in England to obtain data on asbestos management. However, a response was not mandatory and at the close just 25% of schools had replied; currently their responses are being analysed. Finally, after fifty years of keeping

the facts from the public, the review also recommended a policy of openness should be adopted; in future, parents would be made aware of the standards of asbestos management in their children's school.

### **Concluding Thoughts**

Britain has the worst incidence of mesothelioma in the world and it is increasing; 39.9 per million of the population per annum [48], compared to the USA which has stabilised since 1999 at 12.8 per million per annum [49]. An increasing proportion of the deaths are amongst people who have never worked in high-risk occupations. It is reasonable to conjecture that a significant contributory factor is that generations of children in Britain have been exposed to asbestos at school. This could start processes involved in the development of mesothelioma at a very young age in a large number of people; all asbestos exposures are cumulative and increase the likelihood of mesothelioma developing [50] so that any later exposures then add to the childhood exposures.

The deaths – of schoolteachers, school support staff, and former pupils – occurring now are a direct result of government policies of the past. Fifty years ago, those responsible for these policies were warned of the dangers by acknowledged experts, but chose instead to listen to advice from a small coterie of individuals within government departments and the asbestos industry. It was expedient to maintain the status quo so as not to alarm the public; even if this entailed manipulating awkward evidence. What was to be avoided was a public outcry calling for immediate removal of asbestos from all schools, a prospect seen to be too expensive to countenance; governments were persuaded that it was better to keep the facts from public scrutiny, and provide ever more expansive reassurances that all was well.

Nevertheless, in the last few years the whole issue of asbestos in schools has been brought into the open, and senior officials now in the Department for Education have distanced themselves from the unjustified assurances given by their predecessors and the department's flawed policies of the past. The process of addressing the problem has begun. There now needs to be an honest assessment of the scale of asbestos in schools and the level of risk for school staff and pupils – and the unembellished results must be made public.

Given the nature of schools and the way they are used, radical measures will be required to halt the carnage that has been exacerbated by decades of misguided government policies. In deciding how drastic such measures should be, those responsible for the safety in schools must, above all, take into account the particular vulnerability of children with regard to asbestos exposure. A phased asbestos removal program for schools, though expensive, would at least eventually lead to the elimination of any risk of exposure for future generations. While asbestos

remains present in school buildings if it is accessible to children there is always the risk of accidental release of fibres, no matter what safety regimes are in place.

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## ASBESTOS AND THE GMB

John McClean, National Health and Safety Officer of the GMB (retired)  
Coordinator of the Asbestos in Schools Group

When Will Thorne MP, who was also the first General Secretary of the GMWU (the precursor to the GMB), stood up in the House of Commons in 1932 to ask a question on behalf of his constituents in the London borough of Barking it was probably the first recorded reference to asbestos by the trade union.

This had followed the Merewether report on asbestos exposure in factories, some of which were situated in Barking, that had highlighted the high exposure to dust in the workplaces where asbestos was being used.

Initial concerns centred on breathing difficulties workers were experiencing; there was no common knowledge of the long-term consequences of asbestos fibre exposure. Indeed, it would probably be fair to say that well into the 1960s trade unions often considered that the best way of representing their members was to negotiate extra payments for dirty or dusty work, without necessarily looking to deal with the hazard involved.

With the link between mesothelioma and asbestos exposure becoming clearer in 1965, trade unions had to begin to take a different approach which gained greater focus with the passing of the Health and Safety at Work Act 1974. From this came the Safety Representatives and Safety Committee Regulations 1977.

When trade unions realized the opportunities this gave them to represent their members on health, safety and welfare issues they started to appoint specialist officers to help provide guidance and advice. The first National Health and Safety Officer appointed by GMB was Dave Gee, who had an industrial background in chemistry.

Obviously the new role took a time to establish and was initially concerned with tackling traditional problems encountered by what was still then predominantly a manual workers trade union, and drawing up guidance manuals on a wide range of issues. The GMB as a general union has members in a number of sectors, both public and private, right across the economy, so asbestos was only one of many concerns raised by members and their officers.

It was becoming obvious in the 1980s that deaths from asbestos related diseases were growing annually. In response to this, as well as campaigning on asbestos issues at local, regional and national levels, much greater effort was directed into fighting for compensation for victims and their families. As now, this often involved establishing case law against intransigent insurance companies.

After Dave Gee came Nigel Bryson who arrived in 1990 with a trade union background. Nigel also had a good working relationship with Stephen Hughes MEP and they both shared a background in North East England. This relationship became increasingly important as trade unionists were often looking to Europe to secure improvements in employment and health & safety legislation, particularly during the 18 years of Conservative rule. The national health and safety department also developed more professional material on asbestos, both for guidance, and in eye catching posters, raising awareness of the asbestos problem in many workplaces.

Following Nigel's departure there was a period of re-organisation to deal with some internal financial difficulties, which left the focus on health and safety in general and on asbestos in particular on a less satisfactory level. Obviously, work continued on giving advice to members and officers, and dealing with government initiatives, but there was little scope for proactive campaigning.

When I was appointed National Health and Safety Officer in 2005 it was with a brief to restore the GMB's reputation as a campaigning trade union, focusing on those issues that were important to GMB members – and due to our history, asbestos featured high on the list. The three lobbies on pleural plaque compensation that we organised, while high profile, did not produce the result we felt victims deserved – a major disappointment under a Labour government. There was more success for the campaign for the universal provision of Alimta, a palliative drug which also helped extend life for mesothelioma sufferers – putting an end to the “post code lottery” implicit in supply from local NHS trusts.

Involvement in HSE campaigns such as the Hidden Killer campaign, designed to raise the profile of asbestos awareness among building workers mainly engaged in refurbishment work, was deemed a success, and responding to government consultations on proposed changes to asbestos legislation ensured that the worker's voice continued to be heard. Working alongside the asbestos victims support groups on issues such as the paying of compensation to those victims of exposure who could not trace their original workplace insurer took time but was ultimately worth it.

At a European level, meetings organised by the European Federation of Building and Woodworkers (EFBWW) helped develop a wider perspective and establish a common approach across Europe while recognizing different speeds of achievement, particu-

larly in those East European countries where history and a lack of resources hindered progress. The GMB was able to help Stephen Hughes with his asbestos Bill which was presented, and agreed, in the European Parliament in 2014 shortly before he stood down.

In conjunction with International Ban Asbestos Secretariat (IBAS), the GMB also organised demonstrations on Canada Day outside the Canadian High Commission to highlight the hypocrisy of Canada's own non-use of asbestos but continued exportation. Thankfully, this has now stopped and our attention has turned to Russia which continues to expose both its own citizens and workers in Asia to this deadly substance.

The most satisfying recent aspect in campaigning on asbestos, however, has come with involvement in the Asbestos in Schools campaign. In 2009, the education unions asked the unions representing school support staff such as teaching assistants, cooks, cleaners and caretakers to join the campaign. This led to Unison, Unite, UCATT and the GMB joining in what has been a productive collaboration. As might be expected, progress has not been easy but headway has been made in getting the department for Education (DfE) to begin to realize the scale of the

problem caused by successive governments effectively ignoring the problem and leaving their successors to deal with it. Much of this work has been driven by Michael Lees, MBE, whose determination and refusal to be sidelined by the civil service has been an inspiration to all who have been involved. Michael has recently stepped down and, as I was on the verge of retiring from the GMB, I was asked to take over the leadership of the campaign.

Inside the GMB my successor, Dan Shears, is determined that the legacy of our work on asbestos over the years will not be wasted and intends to continue the union's involvement in the Asbestos in Schools campaign, and in other areas such as highlighting Action Mesothelioma Day and speaking on asbestos issues on Workers Memorial Day. Considering the latency period from exposure to disease and the presence of asbestos in so many buildings the union supports an asbestos eradication policy along the lines of that set out in the recent motion adopted by the Asbestos Sub-group of the All Party Parliamentary Occupational Safety and Health Group.

Until asbestos has been removed, safely, from all buildings trade unions such as the GMB will have no option but to continue to fight for their members and the wider public on asbestos exposure.



Pleural plaques rally, Westminster 25 June 2007

# UNITE'S ASBESTOS CAMPAIGN: ASBESTOS – BANNED BUT NOT GONE; ALL ASBESTOS CAUSES CANCER

Susan Murray, National Health and Safety Adviser of Unite

Asbestos is the single greatest cause of work-related deaths in Britain: at least 5,000 a year, and rising – a damning indictment of corporate negligence.

Unite launched a new asbestos campaign in January 2015. The accompanying “campaign pack” aims to raise awareness of asbestos among members and safety representatives and to provide information for members about asbestos related diseases, the Unite asbestos register and asbestos personal injury compensation claims. With around 15,000 Unite members already signed up to the Unite asbestos register (which is for members who believe they have been exposed to asbestos at work), the matter is very urgent.

## **Rotterdam Convention Refuses to List Chrysotile in their Right to Know Provisions**

Though the UK is one of more than 50 countries in the world that have banned the use of asbestos (since 1999 in the UK) asbestos is not gone. It is still present in many workplaces including schools, hospitals, public buildings, factories and railway premises and must be managed safely under health and safety legislation. And, as readers will know, exposure to **all** forms of asbestos can cause cancer.

Unite, together with Australian manufacturing and construction unions the AMWU and CFMEU joined forces with victims' groups and the global unions the BWI and IndustriALL on 12 May 2015 in an international asbestos protest outside the United Nations building in Geneva.

The demonstration took place as government representatives from over 160 countries were participating in the Rotterdam Convention conference to decide whether to list chrysotile (white asbestos) as a dangerous substance under the Convention (Annex III). Other forms of asbestos are already listed, as are a number of dangerous pesticides and other chemicals.

Because the decisions of the Convention have to be made by consensus, it is all too easy for countries which have vested interests in the mining and manufacture of asbestos to exercise a veto. On this occasion (the 5<sup>th</sup> time that chrysotile was up for discussion) the listing was again blocked – by the Russian Federation, Kyrgyzstan and Zimbabwe. The matter will now be deferred (again) to the 8th meeting of the Convention in 2017.

The action by unions and asbestos victims did not go unnoticed. *The Earth Negotiations Bulletin* reported that the president of the conference noted a level of activity he had not experienced in 15 years. This in-

cluded a plea for listing of chrysotile from an Indian worker who, after working with chrysotile asbestos for 40 years, suffers from asbestosis.

## **Lobbying the UK Government on the Rotterdam Convention**

In response to a request from Building Workers International prior to the convention meeting, Unite had written to both the relevant government minister and the shadow minister for employment to urge them to do everything they could to ensure the listing of chrysotile under the convention.

## **An Asbestos Eradication Law is Urgently Needed**

Unite supports a global ban on asbestos. The only way to prevent more asbestos deaths is to remove all asbestos still present in buildings and ensure that it is disposed of safely and never reused. To accomplish this much stronger legislation in Britain is required. That is why we support and welcome the All Party Parliamentary Group on Occupational Safety and Health's decision in June 2015 to call for a new law on asbestos, with a clear timetable for the eradication of asbestos from every single workplace in Britain.

We also support the group's call for health and safety enforcement authorities to develop workplace inspection programmes to verify that all asbestos is marked and managed, and that asbestos eradication plans are in place – and be properly resourced to carry out this regulatory activity.

## **Killer Dust in Schools: the Joint Union Asbestos Committee**

Unite is part of the Joint Union Asbestos Committee working with the nine other unions that have members working in schools. The ultimate aim of the union campaign is to remove all asbestos in our schools.

Unite is also involved in the Asbestos in Schools working group; a tripartite group, including MPs, DfE, local government and asbestos removal contractor representatives, which is also working on the issue.

The campaign and awareness raising through social media, lobbying, and responding to DfE consultations have resulted in several positive developments, including a review of the DfE's policy on managing asbestos in schools and updated online guidance on asbestos management. Unite will continue to work alongside the other school unions to achieve the removal of all asbestos from schools.

For more information about the Rotterdam Convention, see:

<http://www.iisd.ca/download/pdf/enb15228e.pdf>

IndustriALL's coverage of the May 12 demonstration, together with photos and a video of a speech by their Health, Safety and Environment Director, Brian Kohler can be seen at:

<http://www.industriall-union.org/global-union-action-against-asbestos>

Unite's asbestos pack is available at:

<http://www.unitetheunion.org/unite-at-work/informationresources/healthsafetyresources/asbestos/>

**Unite - the union** THE FIGHTING BACK UNION  
[www.unitetheunion.org](http://www.unitetheunion.org)



**ASBESTOS Banned but not gone**

**ASBESTOS KILLS**

Your Unite rep is:

**unite the UNION**

LA03403-002/0716 11/09/13



**ASBESTOS KILLS**

**ASBESTOS: BANNED BUT NOT GONE. ALL ASBESTOS CAN CAUSE CANCER**

**Danger Asbestos**

If you have been diagnosed with an asbestos disease you should contact Unite's legal service without delay by calling **0800 709 007** for free, specialist legal advice and support from a Unite solicitor.

Your Unite Representative:

**unite the UNION**

[www.unitetheunion.org](http://www.unitetheunion.org)

ES/6718-444/12-14

## RIGHT TO KNOW: ASBESTOS IN SCHOOL WALES – A LONG AND WINDING ROAD!

Cenric Clement-Evans, Spokesperson for the Right to Know: Asbestos in School Wales Campaign  
Secretary of the Cross Party Group on Asbestos in the Fourth National Assembly (Wales)

In early 2012 the All Party Parliamentary Group on Occupational Health (APPGOH) published its impressive report “Asbestos in Schools – the Need for Action.”

A number of us came together to see what could be done for Schools in Wales, particularly as the powers with regard to both health and education are devolved to the National Assembly for Wales. This led to the launch of the Right to Know Campaign (see: <http://www.righttoknowasbestos.org/>), which coincided with the closure of Cwmcarn High School in Caerphilly due to the poor condition of asbestos present. The school remained closed for 14 months with considerable disruption for the pupils and all working there.

The campaign has been supported by (to name but a few) the Joint Union Asbestos Committee, the Asbestos in Schools Group, the Wales TUC, many individual trade unions and also a number of cancer charities here in Wales; this support has been an enormous source of strength for the campaign. It will come as no surprise to anyone that Michael Lees has been my rock throughout.

An integral part of the campaign was the Asbestos in Schools Petition (P-04-522), which we submitted to the Petitions Committee for the National Assembly. It was available for signature from late 2012 onwards. It built upon one of the APPGOH’s key recommendations, namely:

“A policy of openness should be adopted. Parents, teachers and support staff should be annually updated on the presence of asbestos in their schools and the measures that are being taken to manage it.”

It focused on parents and guardians having the “right to know,” as under the Control of Asbestos Regulations there is no duty to inform them. The petition (which can be found at <http://www.senedd.assembly.wales/mgIssueHistoryHome.aspx?IId=8437&Opt=0>) was worded as follows:

“We call on the National Assembly for Wales to urge the Welsh Government to put measures in place to ensure that parents and guardians of children across Wales can easily access information about the presence and management of asbestos in all school buildings.

Given the health risks associated with the presence of asbestos in public buildings, we believe

parents and guardians across Wales have the right:

- to know if asbestos is located in their school;
- to know whether, where asbestos is present, it is being managed in line with the Control of Asbestos Regulations 2012;
- to access that information easily online.”

Such is the importance of the petition that it has been considered on 12 occasions already by the Petitions Committee, including during two evidence sessions. Full details of all the meetings and the correspondence are available online (see <http://www.senedd.assembly.wales/ieIssueDetails.aspx?IId=8437&PlanId=0&Opt=3#AI14187>), including correspondence between the committee and the Minister for Education and Skills Huw Lewis AM and contributions from the Health and Safety Executive and the Wales TUC.

In short, the position of the Welsh Government has been that the issue of asbestos in schools is a matter of health and safety and therefore not within their power or responsibility. This is despite it being made clear by the UK Government in statements made by ministers in both the House of Commons and House of Lords, that responsibility for policy and management of the issue rests with Welsh Government (for more information please see my article in ClickonWales “Asbestos Ping-Pong between Cardiff Bay and Westminster” <http://www.clickonwales.org/2014/04/asbestos-ping-pong-between-cardiff-bay-and-westminster/>).

As recently as 16 July 2015 in the Senedd, assembly member Janet Finch-Saunders raised the issue of a college lecturer who had died from mesothelioma and asked specifically “...can you assure me what steps you are taking as Minister to safeguard our teaching staff and pupils from the danger of asbestos within our school or college buildings?”

The Minister for Education and Schools responded:

“... I remind Members that the Welsh Government has no direct responsibility in this regard: it is a matter for the owners – usually local authorities – and for the Health and Safety Executive. Officials will review existing guidance for Wales with key stakeholders such as NHS

Wales, HSE Wales and Welsh Government public health colleagues to ensure information remains current and accurate. My officials are currently organising this process with a view to completing it early in the new academic year. We will also maintain a watching brief during the design of the UK Government's air sampling study."

In May 2015, briefly heartened by what appeared to be a softening of the minister's stance, and in a letter to the (National Assembly) Petitions Committee, I first called for an asbestos in schools steering group to be set up, similar to that set up by the Department for Education at Westminster:

"As the Minister is aware the Department for Education Asbestos in Schools Steering Group was established to improve the asbestos management in schools. Its members are drawn from a wide range of disciplines and expertise. It is chaired by a senior civil servant and reports to the Minister. The Group both recommended that an assessment should be made of the asbestos risks to children and also that a review should be carried out of asbestos policy in schools. ... I would very much urge the Department for Education and Skills to set up a similar steering group, so that when deciding upon policy it benefits from the wisdom and experience of many different voices. In particular, such a group should be led by the Department and include Assembly Members, members representing local authorities, governors, trade unions, health professionals, the HSE and asbestos experts."

On the 30 July 2015, asbestos in Welsh schools being the main story both in the Welsh and the English BBC News (see: <http://www.bbc.co.uk/news/uk-wales-33708601>) considerably helped raise awareness of the campaign, and I was able to highlight my call for a steering group on air:

"I don't care who takes responsibility, I want somebody to take responsibility."

"This is too important to get embroiled in some form of party politics or some big issues between the Welsh Government and the UK Government."

"I think that the way is fairly straightforward, not the managing of the issue but the putting together of a steering group, deciding policy."

"I don't think it's difficult to start that ball rolling."

However, writing to the Petitions Committee on the 15 July (albeit unseen by me until September) the minister dismissed any idea of a Welsh steering group when he stated (including some factual errors) that:

"The steering group in England was set up to review the policy of Asbestos Management in Schools in England following the statement of the Committee of Carcinogenicity in 2013. Following the publishing of these review findings we are satisfied that the work carried out by this group of experts will provide sufficient information for Welsh Government to deal with the issue of asbestos at this time. However, I will continue to maintain close contact with the UK Government Department of Education (DfE) as they develop their plan for improving their evidence base, and I will review our policy once these findings are made public."

On 20 October I gave evidence to the Petitions Committee including reading sections from an email received from the Chair of the DfE Asbestos in Schools Steering Group the previous day which confirmed that:

"The Department for Education's remit is for schools in England. As such, the Asbestos in Schools Steering Group ... only covers the issue of asbestos management in schools in England ..."

"... The remit of the committee means it has not received specific representations on behalf of schools in Wales ..."

"... Focussing on schools in England enables the group to consider the specific issues faced by English schools, which exist in a different policy framework to those in Wales. I would therefore suggest it is right that the remit of the Steering Group is to consider schools in England."

Whatever contact there may have been with the DfE steering group and the Ministry for Education and Skills it is clear that there has been no presence and therefore no representation at the DfE steering group meetings.

On 24 November 2015, the minister himself gave evidence to the Petitions Committee (see: <http://senedd.tv/Meeting/Archive/cdae8dbd-2458-4ed1-a1a6-cb2ad3f0535b?autostart=True>).

In terms of Welsh Government responsibility he stated:

"Our role is primarily to support the duty holder. It's also, of course, to be aware of developments that might be happening elsewhere in the UK and respond accordingly, and to ensure that current guidance is being adhered to. We regularly review that guidance. ..."

"Our role in Welsh Government is an enabling role, I suppose, and one of ensuring that information that's available is up to date, that it's as rigorous as it can possibly be, in terms of guidance, and that we're on top of any devel-

opments in the field that might lead us to the conclusion that we need to tighten up procedures in any particular area.”

Later in his evidence he revealed, for the first time publicly as far as I am aware, that a “working group” had been set up when he stated:

“We may not be a part of the English steering group, but we have our own working group and we do observe on the English working group. We have interplay between officials in terms of making sure that [for] anything that goes on in England we’re absolutely satisfied here in Wales that we’re doing something that is at least as rigorous in terms of those issues. ...”

“As to observing, I can only repeat that I am not aware of anyone from Wales having attended the DfE steering group.”

When pressed, the minister was unable to name members of the “working group” but said “we have the NHS, the Health and Safety Executive, Public Health Wales, and Welsh Government.”

Seemingly the group had been set up and met in July 2015, and was due to meet again in early 2016, after the next DfE Steering Group meeting (which it did on 25 January 2016\*). Astonishingly, leaving aside issues of transparency and accountability, the group had been established without any worker representation or input, let alone advice from any other non-governmental sources.

Later, the minister stated: “What the group is there to do at the moment is to reassure Welsh Government, and by extension the Welsh public, that we are as up to date as we can possibly be and that there is no shortfall in terms of the way that we approach this very serious issue in Wales, as compared to how it

may be approached elsewhere in the UK or further afield.”

How the Welsh public can be reassured by such a cosy setup remains to be seen.

There is much more of concern in the evidence of the minister, including his assertion that providing online data would be too much of a burden on local authorities, despite the fact that it is their duty to collate data and what better way of storing it than digitally?

Perhaps however of greatest concern was the minister’s statement that: “It’s worth bearing in mind also that it’s not just schools that contain asbestos; right across the public realm and, indeed, the domestic realm, we spent 30 years building this stuff into our buildings, and it’s ubiquitous – this stuff is all around us all the time, unless we’re spending all our time in very modern buildings.” Which seemed tantamount to his saying that it is there and there is nothing to be done about it, so let’s try not to disturb it.

So what happens next and what in a short space of time have we achieved?

The campaign must go on to ensure that government whether that be in Cardiff Bay or Westminster takes responsibility for the issue of asbestos in schools in Wales.

We have considerably raised awareness of the issue in Wales and the media are interested.

We may have, in our early work, contributed to the production of guidance by the Welsh Government. We may have contributed to the formation of the “working group” which whilst far from ideal is better than no group at all.

We are not downhearted!

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\*Welsh Government sources confirmed that the Asbestos Management in Schools Working Group [Wales] met on 25 January 2016 and that the group comprised representatives from HSE Wales, Public Health/NHS Wales and the Welsh Government, and “following group discussions it was agreed that at guidance and policy decision stages additional key stakeholder groups should be consulted, including the teaching unions.” We have also since learned that a representative from the Welsh Government attended the DfE Steering Group meeting (for the first time) on 30 March 2016.

# PLEURAL PLAQUES AND NEGLECTED SOCIAL JUSTICE ISSUES

Tommy Gorman, Jim McCourt, Andrew Watterson, Occupational and Environmental Health Research Group, School of Health Sciences, University of Stirling

According to the Centers for Disease Control USA, approximately 50% of all individuals who were regularly exposed to asbestos develop pleural plaques and 20-50% of people with pleural plaques get diagnosed with this condition. About a third to one half of those occupationally exposed to asbestos will have calcified pleural plaques thirty years after first exposure (Reinhartz 2004). A leading Scottish physician estimates that 70-80% of mesothelioma patients have asbestos-related pleural plaques (Discussion 22/08/2015).

The Scottish Government estimates that people with pleural plaques who have been heavily exposed to asbestos at work have a risk of mesothelioma more than one thousand times greater than the general population (Scottish Government press statement 14 October 2011).

Recent research highlights the differing treatment of people who develop pleural plaques in Scotland and Northern Ireland compared with those in England and Wales.

A discussion paper from the University of Stirling, Occupational and Environmental Health Research Group (OEHRG) “*Pleural Plaques: Obtaining Social Justice and Equity in Addressing Compensation Issues in Scotland*” has highlighted a number of concerns in the civil compensation process as it applies to people in Scotland who have been exposed to asbestos. These are focused on people who have made a claim for pleural plaques or pleural thickening and then agree to accept what is known as a full and final settlement from an insurance company or former employer to conclude a civil damages case.

Those who agree to accept a full and final settlement in preference to a provisional settlement for pleural plaques or pleural thickening not only preclude themselves from bringing a future claim but also may hinder any family member claims for damages.

The OEHRG paper argues settlements in pleural plaques cases should have “stand alone” status and hence have no bearing on any future settlement. The preferred outcome is that in pleural plaques cases the victims are paid at least the current full and final level. Pleural plaques, as confirmed by the Supreme Court October 2011 judgement, have no influence on a future diagnosis of mesothelioma, lung cancer, asbestosis or pleural thickening.

## Background

From the 1980s onwards, courts throughout the UK made compensation awards for pleural plaques due to negligent exposure to asbestos. Those awards were

paid by the negligent party or their insurer. However, on 17 October 2007 the House of Lords unanimously ruled in *Johnston v NEI International Combustion Ltd* and conjoined cases, that asymptomatic pleural plaques do not give rise to a cause actionable for civil compensation.

On 23 June 2008, the Scottish Government introduced the Damages (Asbestos-related Conditions) (Scotland) Bill. This measure was intended to ensure that people negligently exposed to asbestos in Scotland who go on to develop certain asbestos-related conditions, can continue to raise and pursue damages actions. The Bill received royal assent on 17 April 2009 to become the Damages (Asbestos-related Conditions) (Scotland) Act 2009. In doing so, it ensured that the House of Lords judgement (*Johnston v NEI International Combustion Ltd*), which ruled un-animously that pleural plaques do not give rise to a cause of action under the law of damages in England and Wales, was not followed in Scotland. The Scottish legislation did not have an impact in England and Wales, where the UK Government in February 2010 decided against passing legislation intended to change the law on pleural plaques. This paper briefly explores the opportunities to build on the progressive actions already taken by the Scottish Parliament.

The Northern Ireland Assembly introduced the Damages (Asbestos-related Conditions) Act (Northern Ireland) 2011 following the lead of the Scottish Parliament.

## Insurers’ Appeal

A number of insurers including Aviva, AXA Insurance, RSA and Zurich sought to challenge the Damages (Asbestos-related Conditions) (Scotland) Act 2009 by way of judicial review. Their challenge was dismissed by the Scottish Court of Session. The insurers complained the Act infringed their human rights and that the decision to bring forth the Damages (Asbestos-related Conditions) (Scotland) Act 2009 was irrational, disproportionate and contrary to the European Convention on Human Rights (ECHR). They further argued the insurance companies would be deprived of their assets to settle claims under the law and this interfered with their right to property under the ECHR. The insurers additionally sought on similar grounds to overturn a decision from the Scottish Court of Appeal.

The insurers’ petition was dismissed by the Outer House of the Court of Session and, on appeal, by the Inner House of the Court of Session. The insurers then appealed to the UK Supreme Court. On 12 October 2011 the UK Supreme Court rejected the appeal and ruled that the 2009 Act was within the

competence of the Scottish Parliament.

The Scottish Parliament opinion is clearly stated in Section 1 paragraph 1 of the 2009 Act: "*Asbestos-related pleural plaques are a personal injury which is not negligible.*" This is despite a widely amplified view that pleural plaques are an asymptomatic condition. The Supreme Court view also noted "*Pleural plaques are physical changes in the tissue which lines the lungs and the chest wall.*"

### **Asymptomatic Condition?**

These opinions are in line with recent scientific research. For example, the Environmental Protection Agency (EPA), Washington DC, USA conducted a systematic review of the association between pleural plaques and changes in lung function in asbestos-exposed populations and concluded that the presence of pleural plaques was associated with statistically significant decrements in forced vital capacity (FVC) and forced expiratory volume (FEV). The study showed that plaques and measured lung function relative to predicted lung function both worsen over time even without additional asbestos exposure.

### **Scottish Law**

The UK Supreme Court's 2011 decision rejected the insurance companies' arguments and Scotland continues to lead the UK in recognizing the rights of asbestos sufferers and bereaved relatives with four pieces of progressive asbestos legislation since 2006, including the Damages (Asbestos-related conditions) (Scotland) Act 2009, which reinforces the rights of asbestos sufferers and their relatives to compensation for exposure to asbestos dust. Much of this legislation received cross-party support in the Scottish Parliament.

Members of the trade union UNITE Thermal Insulating Engineers SC/162 branch, with a long and distinguished history of campaigning for social and economic justice on behalf of their peers, began to campaign on this issue with other parties several years ago. The branch were and are concerned at the way in which pleural plaques cases are being and have been settled under the current legal process. They consider the Scottish Parliament Justice Committee should investigate any circumstances that could result in bereaved relatives being disadvantaged through an inability to exercise their legal entitlement. They wish to highlight that victims of pleural plaques and pleural thickening may be advised by a solicitor, acting on their behalf, that they have two choices: either they can accept a provisional payment as it allows them to go back to court if they contract a more serious asbestos-related disease or they can accept a full and final payment which ends all legal liability against the defender.

Drawing on the case histories provided by Unite and others, the University of Stirling report, makes a number of recommendations it believes should be supported by all organisations committed to improv-

ing the life experience of people who have been exposed to asbestos in Scotland:

1. The Scottish Parliament Justice Committee should examine the social benefits of an alternative payment system in appropriate categories of asbestos claims in Scotland.
2. The Scottish Parliament Welfare Reform Committee should examine the social benefits of an alternative payment system in appropriate categories of asbestos claims in Scotland and consider the merits of an alternative solution to the current arrangements.
3. The Scottish Parliament Justice Committee should examine the economic benefits of an alternative payment system in appropriate categories of asbestos claims in Scotland.
4. The Scottish Parliament Justice Committee should examine the presence of any anomalies in the current settlement process of asbestos claims in Scotland.
5. Claimants should be paid what they are due in full with no effect on future unforeseeable health outcomes.
6. The Scottish Parliament Justice Committee should examine any possible negative impact on women within the asbestos compensation process and identify appropriate remedies.

### **Moving Forward**

All potential disadvantages should be removed from the rights of bereaved relatives in the spirit of the ethical aims of Scottish Parliament legislation. While researching the paper concerns arose regarding potential gender inequality within the pleural plaques compensation process in Scotland which needs to be explored further. There is a negative impact on women if the rights of relatives to damages are not clarified in respect of provisional and full and final settlements. Additionally, female claimants find it more difficult than their male counterparts to secure compensation for pleural plaques and other asbestos-related conditions.

At a recent (September 2015) meeting in the Scottish Parliament, Pat Rafferty Scottish Secretary of UNITE and leading Scottish author and Booker Prize winner James Kelman spoke in support of the Stirling proposal.

As well as improving the position for people in Scotland perhaps the Stirling paper might act as a catalyst for change throughout the UK and beyond. It may provide a focus to discuss the overall situation regarding pleural plaques compensation and address the injustice inflicted on pleural plaques sufferers in England and Wales in 2010 with a campaign supported by asbestos support groups, trade unions and others who are sympathetic to reversing this situation.

## ARMLEY: “TOO CLOSE TO HOME”

Vanessa Bridge and Adrian Budgen, Trustees of the June Hancock Mesothelioma Research Fund

Twenty years ago, on 2 April 1996, a landmark judgment in favour of two Leeds residents brought up in the shadow of an asbestos factory was handed down in the Court of Appeal in London. Repercussions of the Court’s decision in the case of Margereson and Hancock v J.W.Roberts Ltd. would echo across the UK and as far afield as South Africa [1], where poor, black communities had suffered a similar fate to working class areas of Yorkshire and Lancashire, their environments poisoned by deadly asbestos fibres released by the asbestos mining or processing operations of companies that denied knowledge of potential consequences. The claimants had fought to prove that the likes of Cape Asbestos and Turner & Newall (the parent company of JW Roberts following a merger in 1920) had failed in their duty of care not just to their workforces, but also to those who lived in the shadow of their industrial sites.

The Leeds claimants June Hancock and Arthur Margereson, born in 1936 and 1925 respectively, lived a few streets apart on an estate surrounding the J.W. Roberts asbestos factory in Canal Road, Armley, Leeds. As children, they played with asbestos as it was regularly pumped out through the factory’s ventilation system and “swirled like snowflakes” through the streets, drifting in piles on windowsills and other surfaces. Children would gather to roll marbles, spin tops and play hopscotch on the factory’s asbestos loading bay, one of the few flat areas in their hilly neighbourhood, and they jumped on bales of processed asbestos. An aerial photograph of Armley Clock School featured its playground covered by a white carpet of asbestos dust; the children played here and the littler ones would even take afternoon naps on camp beds.

Decades later, many residents paid a terrible price. The estate was found to have the highest UK incidence of mesothelioma [1]; an incurable type of cancer with an incubation period stretching into decades, the only known cause of which was asbestos exposure. June Hancock’s mother Maie Gelder died of it in 1982; when June herself was diagnosed with the same disease twelve years later, she vowed to take on the multinational whose negligence she believed had caused her mother’s premature death, and would likewise rob her of old age and seeing the births of her grand-children.

The Armley factory began producing textiles in 1874; some twenty years later it embraced asbestos technology going on to become one of the UK’s

biggest producers of asbestos insulation and asbestos-containing fireproofing products, exporting to some 60 countries worldwide. The company would later claim it could not have known about the effects of asbestos exposure until well beyond the years when June Hancock and Arthur Margereson played in Armley’s streets. Local doctors who recorded the effects of these industrial processes told a different story. The UK’s first named asbestos victim was Nellie Kershaw, who left school at 12 to work briefly in a cotton mill, then in Turner Brothers’ Asbestos mill, retiring of ill health in 1922 and dying two years later at the age of 33 of pulmonary asbestosis. As a result of her death and others like it, the UK’s first asbestos regulations were introduced in 1931.

Over subsequent decades, a range of injuries and disease caused by asbestos production were recorded and written up in the medical literature. It wasn’t until the 1960s, however, that mesothelioma was given a name, although its symptoms and the awful trajectory of the disease were well enough known in the communities affected by it. Two East End doctors, Molly Newhouse and Hilda Thompson, described the incidence of mesothelioma in the community surrounding the Barking factory of Cape Asbestos Co. Ltd., noting that those contracting mesothelioma had been exposed to relatively small amounts of asbestos.

This was what Turner & Newall relied upon, when their lawyers told Leeds Crown Court in 1995 that the company couldn’t possibly have anticipated that a disease not even given a name caused by asbestos exposure would cause injury and claim lives many decades later. They also argued that their responsibilities extended only to their workforce, conveniently overlooking the fact that in the process of sucking dangerous dust out of the factories in order to comply with industrial regulations and as a consequence pumping asbestos into local neighbourhoods, they had exposed hundreds if not thousands of local residents to the same deadly threat.

In the judgment in favour of June Hancock and Arthur Margereson (represented by his widow Evelyn) handed down on 27 October 1995, Mr Justice Holland saw off the company. On behalf of June Hancock, Robin Stewart QC provided the judge with all the argument and evidence required to “tear down the factory walls” – and conclude that the company did indeed owe a duty of care to those living in the shadow of their operations. While sounding the customary warning in “lawyer-speak” – that his judg-

\*Subsequent to this case others would take advantage of the precedent set, with asbestos victims in South Africa successfully mounting a huge lawsuit against Cape, settled in 2003.

ment was not meant to “open the floodgates” for other potential litigants – Mr. Justice Holland went to some trouble to categorise Armley claimants into groups, according to their occupation, address, school and relation to those working in the factory, clearing the way for claims in the city and beyond.

It was the UK’s first case where physical injury was found to have been caused by industrial environmental pollution; the company was found culpable for the effects of its deadly processes outside the factory wall. The implications for the defendants were such that they felt compelled to appeal; the case was fast-tracked (as June Hancock was not well) and within six months, the Court of Appeal bench, chaired by Lord Justice Russell, concurred with Christopher Holland, and refused Turner & Newall

leave to appeal to the House of Lords. Judges in both courts were not unaffected by the conduct of the company throughout both trials “reflecting a wish to contest these claims by any means possible, legitimate or otherwise... simply to obstruct the plaintiff’s road.” Damages for June Hancock were £65,000 and for Arthur Margereson, £50,000; relatively trifling sums for decades of their lives, but the principle was what mattered.

Thus it was that, to paraphrase June, the Goliath of an British multinational was brought to heel by a personal secretary from Armley; “It proves no matter how small you are you can fight,” said June, “and no matter how big you are, you can lose.”

(See: Winnett, Robert (25 June 1995). "Homeowners hit by asbestos clean-up costs". *The Times* (London). p. 1.)

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## ASBESTOS INDUCED LUNG CANCER – PROOF OF CAUSATION

David Allan, QC

On the 15th February 2016 the Court of Appeal handed down judgment in the case of **HENEGHAN v. MANCHESTER DRY DOCKS LIMITED 2016 EWCA Civ. 86**. The claimant had sought damages for losses arising out of Mr. James Heneghan’s contraction of lung cancer and premature death. The lung cancer was caused by occupational exposure to asbestos dust during many years of employment. Six former employers could still be sued and those six were responsible for 35.2% of the deceased’s occupational exposure to asbestos. The issue between the parties was whether each defendant was jointly and severally liable for the whole of the damages, or for only a share proportionate to that defendant’s contribution to the total exposure. At the trial Jay J. held that lung cancer and mesothelioma were legally indistinguishable. In a multi-exposer case, a claimant could only prove causation by reliance on the **FAIRCHILD** principle. It followed in these circumstances that the damages were divisible and a defendant was only liable for his proportionate share. The Court of Appeal has held that the trial Judge’s conclusions were correct. The effect of the Court of Appeal’s judgment is that the **FAIRCHILD** principle is extended to lung cancer cases. An important distinction remains between lung cancer and mesothelioma. Pursuant to Section 3 of the Compensation Act 2006, any tortfeasor materially increasing the risk of mesothelioma is liable for the whole of the loss. The lung cancer victim faces a much greater hurdle than the mesothelioma victim to prove that the disease was caused by asbestos. Having proved that the lung cancer was caused by asbestos exposure, the victim may only recover a proportion of the loss if he or she cannot sue for the entirety of their exposure.

**FAIRCHILD v. GLENHAVEN FUNERAL SERVICES LTD. 2002 UKHL 22** established that a mesothelioma victim could recover damages against any former employer who exposed the victim to asbestos in breach of duty, even though it could not be proved that the particular exposure had caused or contributed to the development of mesothelioma. **BARKER v. CORUS UK LTD. 2006 UKHL 20** widened the scope of the **FAIRCHILD** principle to cover all tortfeasors irrespective of any exposure for which the victim was responsible. However, in **BARKER** the House of Lords held that a defendant was liable only in proportion to his own contribution to the asbestos exposure, and therefore to the risk that the victim would contract mesothelioma. This part of the judgment was rapidly reversed by Section 3 of the 2006 Act, but the Section only applies to mesothelioma.

Until the present case the lung cancer cases which had reached trial had been against a single defendant. In **SHORTELL v. BICAL CONSTRUCTION** (16 May 2008 unreported) the deceased contracted lung cancer and one employer was responsible for all the exposure to asbestos. The issue for the trial Judge was to determine the extent of exposure to asbestos. It was accepted by the parties that exposure greater than 40 to 50 fibre ml/years would more than double the risk of lung cancer and the Court could conclude that asbestos had caused the lung cancer. In **JONES v. SECRETARY OF STATE FOR ENERGY AND CLIMATE CHANGE 2012 EWHC 2936** workers at a smokeless fuel plant claimed damages for a range of conditions which included lung cancer. The workers at the plant had been exposed to carcinogens

in fumes created by the manufacturing process. The trial Judge (Swift J.) held that causation was established for lung cancer if tortious exposure to carcinogens more than doubled the risk of lung cancer. However, if the increase in risk fell short of doubling that risk, then the Court was unable to conclude that tortious exposure had caused or materially contributed to the lung cancer.

In **HENEGHAN** the trial Judge accepted the evidence of the medical expert, Dr. Moore-Gillon, relied on by the defendants. The stochastic nature of cancer was such that one was unable to say, even on a balance of probabilities, that asbestos exposure from each defendant had actually contributed to the development of the lung cancer. One was only able to conclude that exposure had contributed to the risk of the disease. The medical expert, Dr. Rudd, relied on by the Claimant, accepted that it would never be possible to say in a deterministic manner which fibres from which source had actually resulted in the development of the tumour. However, current knowledge of the cellular and molecular processes leading to the emergence of a cancer made it highly improbable that any source had not contributed to the carcinogenic process.

The main judgment in the Court of Appeal was delivered by the Master of the Rolls. He accepted that there were two stages to the causation question. The first question was what caused the lung cancer. Was it asbestos, smoking, or something else? This was a question that was answered by epidemiological evidence. Mr. Heneghan's cumulative asbestos exposure over his working life amounted to 133 fibre/ml years. Of this total about 114 fibre/ml years involved amphibole asbestos. Epidemiology indicated that this exposure was sufficient to increase Mr. Heneghan's risk of lung cancer about five-fold. This was irrespective of his smoking history, and without having regard to the multiplicative effect between asbestos and cigarette smoke. The Master of the Rolls noted that some reservations had been expressed about the doubling of risk test by some members of the Supreme Court in **SIENKIEWICZ v. GRIEF UK LTD. 2011 UKSC 10**. Despite that he held there was no doubt about the validity of applying that test in the present case. The medical experts accepted that but for the asbestos exposure, Mr. Heneghan would probably not have developed lung cancer.

That left the second question: namely in a multi-contributor case, which contributor's asbestos caused the lung cancer? This was labelled the "who" question. It was accepted that where the exposure was predominantly to amphibole asbestos, the threshold for doubling the risk of lung cancer was 25 fibres/ml years. However, none of the defendants individually exposed the deceased to this level of asbestos. The exposure from only one former employer, Blackwells, exceeded this level, and this tortfeasor could no longer be sued.

The argument for the Claimant was that lung cancer and mesothelioma were factually and legally distinguishable. In mesothelioma, the difficulty on causation which lay at the heart of the decision in **FAIRCHILD** was summarised by Lord Bingham at paragraph 7 of the judgment. The medical evidence indicated that a mesothelioma could be caused by a single fibre, a few fibres, or many fibres, and none of these possibilities was more likely than the other. Lord Bingham characterised this situation as a "rock of uncertainty". It led to the modification of the usual causal requirements. In sharp contrast to this situation, lung cancer was only attributable to asbestos after substantial exposure. The threshold of 25 fibre/ml years represented many millions of fibres. The carcinogenic processes which eventually led to the emergence of a cancer involved large numbers of fibres. It was accepted by the medical experts that the distribution of fibres from each source in the lungs was likely to be similar. In contrast to the medical evidence which led to the **FAIRCHILD** judgment, it was argued that the medical evidence in **HENEGHAN** should lead to the conclusion that each tortfeasor who was responsible for a significant proportion of the exposure had materially contributed to the disease. It was not in dispute that lung cancer was an indivisible injury in the sense that once the disease was contracted its severity was not affected by the extent of exposure. It was also not in dispute that the usual common law rule was that in the case of an indivisible injury, a tortfeasor was jointly and severally liable for the loss. Lung cancer had caused Mr. Heneghan's death, and death was the classic indivisible injury.

The Master of the Rolls considered the House of Lords' judgment in **BONNINGTON CASTINGS LTD. v. WARDLOW 1956 AC 613**. In that case he said the tortious dust actually contributed to the disease:

"It contributed to the disease because its severity was proportionate to the amount of dust inhaled and the amount attributable to the swing grinders was material." (Paragraph 27).

The Master of the Rolls contrasted this conclusion with the reasoning of the House of Lords in **McGHEE v. NATIONAL COAL BOARD 1973**. In **McGHEE** the submission that **BONNINGTON CASTINGS** should be applied, was rejected. The judgment of Lord Reid made plain that medical science was not able to say whether the tort of the defendant had actually contributed to Mr. McGhee's dermatitis. It could only say that it had materially increased the risk of the disease occurring:

"McGhee was an application *avant la lettre* of the Fairchild exception."

In conclusion, the Master of the Rolls held that the material contribution test applied in **BONNINGTON CASTINGS** could not be applied in the

present case. It had all the salient features that applied in **FAIRCHILD** and, therefore, the modified approach to causation should be applied to lung cancer. This means it is sufficient to establish causation in a lung cancer case if a claimant proves the cancer was caused by asbestos by satisfying the doubling the risk test and that asbestos exposure with an individual defendant has materially increased the risk of lung cancer. However, the House of Lords' judgment in **BARKER v. CORUS UK LTD.** still represents the common law (see **INTERNATIONAL ENERGY GROUP LTD. v. ZURICH INSURANCE PLC UK 2015 UKSC 33.**) If Section 3 of the Compensation Act 2006 does not apply and a claimant has to rely on the **FAIRCHILD** principle to establish causation, then the liability of each defendant will be proportionate to the contribution to the risk of disease.

The House of Lords' decision in **BARKER** on proportionate recovery was rapidly reversed by Parliament. It is difficult to see why the mesothelioma victim should have the benefit of Section 3, and not the lung cancer victim. If in fact the justification for Section 3 applies with equal force to lung cancer victims, then the case for an extension of Section 3 to include such victims appears to be overwhelming. The lung cancer victim already faces a greater hurdle in proving sufficient asbestos exposure to satisfy the doubling of risk test. It frequently occurs that some tortfeasors responsible for a significant part of the asbestos exposure can no longer be sued. It will be a considerable injustice if a lung cancer victim, having satisfied the doubling of risk test by proving on a conventional basis that their cancer was caused by asbestos, can still only recover a modest proportion of their full loss.

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## ESTIMATION OF FUTURE MALE MESOTHELIOMA DEATHS IN GREAT BRITAIN

Robin Howie, Occupational Hygienist, Robin Howie Associates

Between 1968 and 2013 annual male mesothelioma deaths in Great Britain rose from 114 to 2,123 and totalled 44,131 over that period.

HSE (2015b) and Tan & Warren (2009) predict that annual male mesothelioma deaths will peak at about 2,085 in 2016, that deaths between 2014 and 2033 will be about 36,100, and that total deaths will reach about 61,000 by 2050. These figures indicate that total male mesothelioma deaths between 1968 and 2050 will be about 91,000. If it were assumed that there would be an average of about 0.5 to 1 asbestos-induced lung cancer death per mesothelioma death, over that period total asbestos-induced deaths would be in the range of about 136,000 to 180,000; thus making asbestos by far the greatest cause of occupational deaths in the history of Great Britain.

There has been a change in the age distribution of deaths over the years; between 1968 and 1972, 90% of deaths occurred below age 74 whereas between 2009 and 2013, 50% of deaths occurred above that age.

This change in the age distribution at death could be due to a number of interacting effects; more people are surviving long enough to develop long latent period diseases, such as mesothelioma, and the high incidence of previously early-in-life asbestos-induced diseases such as asbestosis and asbestosis with tuberculosis have declined – presumably as the severity of exposure has reduced and the use of antibiotics increased – so a larger proportion of asbestos exposed persons are surviving to develop mesothelioma. In addition, as there is an inverse relationship between the severity of exposure to asbestos and lat-

ent period, e.g. see Bianchi et al (2001, 1997), it could be expected that those who had experienced only low levels of exposure to asbestos would have longer latent periods and would therefore develop mesothelioma only if they survive into their 70s or older. However, as environmental levels of exposure could have started earlier in life than occupational exposures, e.g. in the home and/or in school, some proportion of the increased latent periods could be offset by earlier exposures. Note that, as a first approximation, each 10 year reduction in age at first exposure below age 30 doubles the mesothelioma risk and that each 10 year increase in life expectancy beyond age 80 also doubles that risk; so children first exposed at age 10 and surviving to age 90 would have an eight times greater risk of developing mesothelioma than equally exposed 30-year-old adults with a 50 year life expectancy.

It is understood that the predictions of future deaths from HSE (2015b) and Tan & Warren (2009) do not take account of future life expectancy as predicted by the Office of National Statistics (ONS).

ONS (2015a, b) indicate that between 1968 and 2013 the number of males aged between 50 and 70 increased by about 25% and will increase by about a further 20-35% by 2050. Between 2012 and 2050 the numbers of males in the higher age bands are predicted to increase progressively by a factor of about 2 for those aged 70-74 to a factor of about 30 for those aged 90+.

Given that men aged over 70 accounted for 72% of male mesothelioma deaths in 2013 the predicted increase of the number of men over that age over the next four decades suggests that mesothelioma num-

bers are going to continue to rise, and rise sharply, for many years.

To determine the number of future mesothelioma deaths it is necessary to convert the number of observed mesothelioma deaths by year and age band into rates per million, extrapolate the rates forward to 2050 (see graph below: Male mesothelioma rates v Age at Death and Year of Death for ages 65-90+), then multiply the predicted rates by the predicted number of men in each age band.

Such calculations have been undertaken based on the HSE (2015a) data for each 5-year age band over 5 year periods between 1969 and 2013 and observed and predicted male numbers from ONS (2015a, b). As the ONS data excluded figures for males aged 90+ between 1981 and 1990 it was assumed from the earlier and later growth in figures for that age group that an annual increase of 2.5% would be valid for the missing years.

No extrapolations were included for ages below 64 as mesothelioma numbers below that age had peaked prior to about 2005 and are unlikely to contribute significantly after about 2016.

The calculations indicate that male mesothelioma deaths will increase progressively from about 11,000 between 2014 and 2019 to about 30,000 between 2045 and 2049. Such increases will be primarily driven by those aged between 80 and 89; but with a significant contribution from those aged 90+. It is estimated that total male mesothelioma deaths will be about 130,000 between 2014 and 2049 and will total about 180,000 between 1969 and 2049, i.e. about twice the figure given by Tan and Warren (2009).

In any such analyses as extrapolations extend further

from the observed data the errors increase. However, as the correlation equations for all 5-year age bands accounted for at least 97% of the observed variability in the data, it is considered that the extrapolations up to about 2029, when deaths between 2014 and that date will total about 40,000, will be reasonably secure.

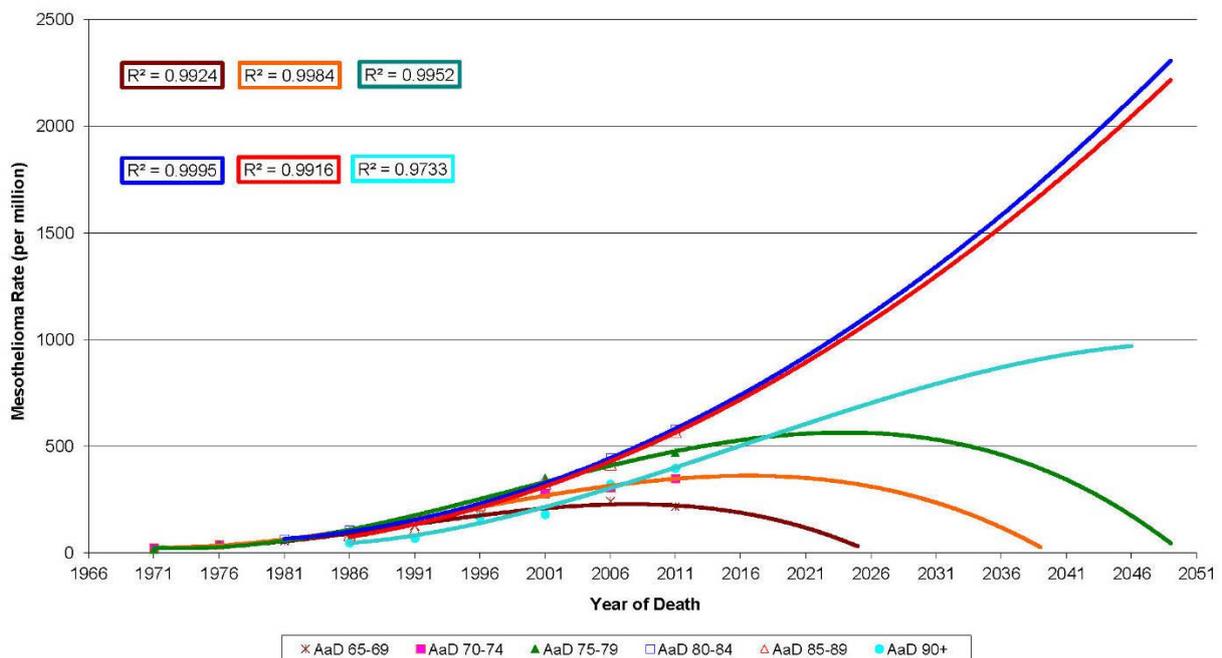
It is relevant to appreciate that men in their 80s in 2030 would have been in their 20s in 1975 and could have worked with, or worked in the vicinity of others working with, materials such as asbestos insulating boards or asbestos insulation products containing amosite, and/or could have disturbed in situ materials containing crocidolite.

Having been involved in about 600 asbestos legal cases over the past 15 years or so, I have observed that many men suffering from one or other of the asbestos-induced diseases tended to have their heaviest exposures to asbestos early in their careers. In the real world dirty or unpleasant jobs tend to be passed to the most junior workmen, or in the case of apprentices, to the most junior apprentice. As early exposures are also the most potent in terms of mesothelioma risk, e.g. see Hodgson and Darnton (2000), it is considered likely that any decline in mesothelioma numbers will not occur until those exposed to amosite in their teens or early twenties reach their 90s, i.e. in about 2045-2055.

**Comment**

Having carried out the above analyses I will be delighted if my predictions are wrong and that HSE's prediction of mesothelioma deaths peaking by about 2020 are correct!

**Male mesothelioma rates v Age at Death and Year of Death for ages 65-90+**



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## BATTLES OVER CHRYSOTILE

Geoffrey Tweedale

When the first issue of the *British Asbestos Newsletter* appeared in 1990, the asbestos industry had racked up over a century of production. Global asbestos output was about 4m tonnes. Another telling statistic was that in 1990 recorded mesothelioma deaths in the UK stood at about 900. Inevitably, much of the coverage of the *Newsletter* over the next quarter century involved the problems of compensating and treating those (and future) victims. By 2013, cases of mesothelioma in the UK had reached over 2,500 a year and showed no sign of slackening. Against this horrifying backdrop, one might have expected that a dominant theme of the *Newsletter* would have been the demise of the asbestos industry. In the early 1990s, global asbestos production did halve; however, since then the output of asbestos fibre has stuck firmly at about 2m tonnes a year.

Why the asbestos industry survived – at least in some countries – is revealed in the pages of the *Newsletter*. The industry fought a sustained rear-guard action. A key plank in the industry's defence has been the argument that asbestos-related diseases are due to amphiboles (blue and brown asbestos) and that chrysotile (white asbestos) poses no health threat and can continue to be manufactured safely. The defence was largely led by chrysotile exporter Canada and supported, at various times, by its allies in government, the medical profession, and the media. Defending chrysotile has been a complex (and often devious) saga. The *Newsletter* has highlighted three areas, where the proponents of asbestos were most active: in scientific forums (such as journals and conferences); in the international arena (which involved global bodies, such as the World Trade Organisation); and in the media.

In the Autumn/Winter issues of 1994, the *Newsletter* noted international moves to "rehabilitate" chrysotile. Four countries – France, Ireland, Portugal, and Spain

– had pressed for a reappraisal of the health effects of asbestos (i.e. chrysotile) by the World Health Organisation. A self-appointed task force began work. Events followed a pattern that would become familiar: it involved a seemingly impressive roster of scientists and officials (such as the International Program on Chemical Safety). But industry funding (via the French) was also to the fore and objections were raised that many of the scientists had industry links. Intertwined with this was a four-day "Chrysotile Workshop," which took place in Jersey in 1993. The *Newsletter* noted the organisers (the IPCS and International Congress on Occupational Health), the contributors to the costs (the asbestos industry and Canadian government), and the overall conclusion – later published in the *Annals of Occupational Hygiene* – that the dangers of chrysotile were minimal and that this would have important economic implications. In other words, that it was still acceptable to mine and process asbestos for profit.

Continued asbestos usage was actively encouraged by Canada and its leading asbestos scientists (mostly based at McGill University in Montreal). The McGill team, led by Corbett C. McDonald, developed a particular view of chrysotile. Drawing upon data from the mining industry (which funded the work), the McGill studies upheld a long cherished view in Canada that working conditions and products were safer than elsewhere and that the dust in Quebec mines was relatively benign. Mesotheliomas (and lung cancers and asbestosis) amongst chrysotile miners were discounted, because they were supposedly due to "contaminants," not chrysotile. Since the main "contaminant" in Canadian chrysotile was identified as tremolite – itself a type of asbestos fibre – this was not a very convincing argument. Conveniently, according to McDonald and the McGill group, Canada had non-tremolite asbestos mines. All that

would be needed for their continued exploitation was “controlled conditions” (respirators and dust extraction) in the consuming industries.

This argument was so riddled with flaws and ambiguities that it seems extraordinary that it was ever countenanced. Everyone was aware that Quebec asbestos mines never screened fibre for contaminants. It was also obvious that this asbestos would be used not in Canada, but in developing countries, where controlled conditions had never existed. However, as the *Newsletter* Spring 1997 observed, the findings were received warmly in some quarters. In 1997, the *Annals of Occupational Hygiene* (sponsored by the British Occupational Hygiene Society) published one of the most defamatory attacks on a group of scientists ever to appear in the scientific literature. The author was McGill scientist (and McDonald collaborator) Doug Liddell. His target was Professor Irving Selikoff and his group at Mount Sinai Hospital, New York, who were sceptical of chrysotile’s supposed merits. Liddell accused them of being motivated by nothing more than “malice” (in contrast to “honest” scientists elsewhere). The article proclaimed the “innocence” of chrysotile. The shabby exercise was topped off by the endorsement of the editor of the journal, who agreed that the American group had ulterior motives (though their precise nature was not stated).

Such shenanigans did not prevent calls for a ban on the mineral in the UK and Europe. The *Newsletter* described in detail the tortuous path to a ban, replete with delays (*Newsletter* Spring 1998), but eventually in 1999 the banning of asbestos was made law in Europe. Even so, the complexities of international law and the linkages of global trade ensured that this break with the past was not clear cut. Over the next few years, the battles over chrysotile became so fraught that the editor of the *Newsletter* (Winter 1998/1999) labelled the ensuing struggle the “Chrysotile Wars.” A key forum for the conflict was the World Trade Organisation, which allowed nation states, in the interests of free trade, to challenge decisions made by other countries. The French decision to ban asbestos was challenged by the Canadian government on the grounds that it was an unwarranted restriction of trade.

The *Newsletter* provided one of the most detailed accounts of events in Geneva, where the Canadian complaint was reviewed in the murky world of secret panels, undisclosed experts, and confidential internal reports. The strategy of the Canadian government, aided by its lobby group the Chrysotile Institute and McGill University science was to overturn the French decision by invoking the mantra of controlled use. They failed. The *Newsletter* Summer 2000 reported that the WTO’s Dispute Resolution Panel had endorsed France’s right to impose a ban. This was a setback for chrysotile producers in the developing

world, but it did not mean the end of asbestos production or the debate about the dangers of chrysotile.

Even in countries without an asbestos industry, the chrysotile issue remained in the news. After 2002, Christopher Booker – a *Sunday Telegraph* columnist (and a former co-founder of the satirical magazine *Private Eye*) – wrote the first of dozens of articles on asbestos. The reason for Booker’s sudden interest in the subject was not immediately apparent: after all, asbestos was now banned in UK. But in 2002, the government had announced regulations to deal with the long-term problem of asbestos already in place in buildings. Commercial property owners now faced the costs of managing and providing an inventory of asbestos in their buildings. Booker comforted them with the argument that the regulations were based on a health and safety “scam” that was based not on science, but on a compensation “racket.” According to Booker, most asbestos in buildings was chrysotile, which was perfectly safe because it did not cause mesothelioma. To counter a voluminous medical literature which stated the opposite, Booker called upon his resident “expert,” John Bridle. The latter operated a consultancy, “Asbestos Watchdog,” to advise property owners (mostly that their asbestos was benign). Bridle was soon describing himself as “professor,” while Booker regarded him as “the world’s foremost authority on asbestos science.” However, in “Connecting the Dots” the *Newsletter* revealed Bridle’s true background and experience, which was not scientific but based on links with the asbestos-cement industry. The *Newsletter* Autumn 2008 highlighted two further exposés of Bridle: one by the BBC and another by George Monbiot in the *Guardian*, 23 September 2008. Bridle’s credentials were described as bogus. His reputation was further undermined, when it was revealed that he had once been prosecuted by a local trading standards department.

Against the background of the WTO deliberations, Canada continued to resist any movement in other countries towards a ban. It financed a “firefighting” trip to Brazil by, inter alia, McDonald and David Bernstein to extol the virtues and safety of chrysotile. American-born Bernstein was described as a “consultant in toxicology.” His scientific output was usually at the behest of industry and fed off the ideas of the McDonald and McGill school. His studies contained little that was new. They were based on rat inhalation studies and recycled the old bio-persistence argument that white asbestos is quickly cleared from the lungs without apparent ill-effects. This view, while being rejected by almost all public health bodies, was congenial to asbestos interests, including the Brazilian Chrysotile Institute, who drew on Bernstein’s bio-persistence theory to claim that white asbestos was safe to mine and manufacture. His views were also sought by the Canadian government, when Health Canada brought together a group of experts to



discuss (yet again) the health effects of chrysotile. The Health Canada report became mired in controversy, because the government blocked its publication. Another dispute arose, too, over Bernstein's involvement. The *Newsletter* Autumn 2008 contrasted Bernstein's claims to be an independent expert with his apparent reluctance to declare any conflicts of interest. In 2007, at a court hearing in Texas, Bernstein had been called to testify at the request of a defendant company in an asbestos case. He was so evasive to direct questions about his funding (prior interrogatories suggested it was over \$400,000) that the exasperated judge interjected:

THE COURT: Just, if you can answer that question ... how much they paid you?

A: Union Carbide asked me to do these studies in order to ....

THE COURT: Can you answer my question please? I'm just repeating the question the attorney asked. Can you answer it or can't you answer it?

A: I can answer how much they paid me, but part of what the sum he's referring to was for actually funding the conduct of the study.

THE COURT: Listen. Can you listen? Can you look at me and listen? Read my lips. How much money did Union Carbide, through their attorneys, pay you?

A: I think ... I don't have the sum in front of me. My recollection is in the order of about a hundred thousand Swiss francs ...

The *Newsletter* Summer 2010 gave a summary of the machinations of global industry lobbyists and the consequences: \$100m in public and private money had been spent in the preceding twenty years to bolster asbestos markets worldwide; however, up to

10m people could die from asbestos-related diseases by 2030. Canada was identified as key in the orchestration and financing of the pro-asbestos lobby.

Eventually, in 2012 Canadian asbestos production ceased and the Chrysotile Institute became defunct. The pro-asbestos mantle, though, simply passed to others. Asbestos lobbying continued through the Chrysotile Association (Russia), the Asbestos Cement Products Manufacturers Association (India), and the Brazilian Chrysotile Institute. These groups represent countries that still mine and use chrysotile. They remain adept at exploiting (and sponsoring) flawed science; and continue to frustrate multilateral attempts to publicise chrysotile as a hazard. When the UN Rotterdam Convention Conference met in Geneva in May 2015, a Russian-led contingent again blocked the listing of chrysotile as a hazardous substance. The Canadian government gave tacit approval to this tactic by declining to support the attempt by a majority of countries to have chrysotile listed.

After 25 years of publication, the *Newsletter's* themes have remained depressingly constant: the appalling and steady rise of asbestos-related deaths (particularly those caused by mesothelioma); the struggle for compensation against the tactics of insurers and an increasingly unsympathetic government; and the manipulation of the scientific and media debate by commercial interests, so that asbestos production can continue untrammelled. The *Newsletter's* strength has been to follow doggedly the chrysotile story as it has been played out across the world. Its pages provide information about the politics of the asbestos industry and the personalities involved (information which is usually missing from the mainstream media, official accounts, or the scientific literature). The *Newsletter* narrative shows why millions of tonnes of asbestos are – unknown to most people – still produced in the world.

## FINAL THOUGHTS

Laurie Kazan-Allen

The vision for this the 100th issue of the British Asbestos Newsletter was not only to reflect on the work we have done over the last 25 years but also to provide a space for our partners to consider Britain's asbestos landscape: past, present and future. Our aim was to be as inclusive as possible and for that reason we reached out to renowned artist Conrad Atkinson to provide an original image for the front cover and expert Geoffrey Beare of the William Heath Robinson Trust to obtain copies of cartoons produced by the famous illustrator Heath Robinson for a 1930s text about asbestos-cement. We would like to acknowledge and thank them both for their efforts. To our knowledge, the Heath Robinson cartoons Mr. Beare made available have remained virtually unseen and unpublished since the 1930s. It was only a vague recollection of having been shown an asbestos drawing in the style of Heath Robinson by a campaigner

one deserves to die from mesothelioma or other asbestos-related diseases; negligent corporations, their insurers and government agencies should be working with the research community to develop a coordinated strategy for the development of new treatments and cures. The export of medical breakthroughs could provide some restitution for the damage done by the British asbestos industry.

The publication of this text comes at a serendipitous time. On 16 March 2016, the Budget presented by the Chancellor to Parliament included the provision of £5 million to establish a National Mesothelioma Centre of Excellence. After so many years of lobbying for research funding for a disease killing thousands every year, this bolt from the blue came as a welcomed surprise albeit one with a sting in its tail [2]. There is no doubt that British research and medical care for mesothelioma patients has improved. In



Artwork [1] by Colombian artist Guillermo Villamizar

in Rochdale many years ago that set me off on the trail of the originals. These illustrations are hugely significant as they document the carefully-honed marketing strategy wielded by British asbestos companies to integrate their products into daily life. Asbestos materials were the future; life without them was, they declared, inconceivable.

The profits of Britain's asbestos industry were paid for by the damaged lives and premature deaths of ordinary men and women; over the decades, the loss of life probably amounts to hundreds of thousands. Unfortunately, more fatalities are to come as the government refuses to engage with the challenge posed by tens of millions of tonnes of toxic products incorporated within the national infrastructure. Unlike Poland and Australia, Britain has no asbestos eradication plan. In the vacuum which exists, hazardous exposures persist and people will continue to die from patently avoidable diseases. Bringing their voices to the fore has always been a key objective of the newsletter and the contributions to this issue by Claire Cowley and Mavis Nye are salient reminders of the daily reality of life with asbestos cancer. No

May, 2016 the International Mesothelioma Interest Group held its 13th bi-annual international conference in Birmingham. The fact that a national research consortium won the bidding process for this event is indicative of the development of our medical expertise and research capacity.

The future will, before long, be in the hands of others. We commend this volume to them as a reminder of the work which has been done and the people who have done it. As Graham Dring writes: "This is a fight for justice, not sympathy – the betrayals of the past will galvanise us to secure justice now and in the future." Until Britain is asbestos-free and asbestos-related diseases have been consigned to the history books, this struggle will continue.

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