Autumn Edition 2022

MESOTHELIOMA UK

MESOTHELIOMA MATTERS

Cover Feature | Page 31

Smiling for the camera at fundraising events

Inside Mesothelioma Matters

Page 2 | First immunotherapy treatment for 14 years approved
Page 4 | Reviewing Action Mesothelioma Day
Page 24 | Charity collaborations fund nursing posts

Photo credit: Nile Ateem

NEWS

Immunotherapy treatment approved for asbestos-related cancer patients in England and Wales

Mesothelioma UK has welcomed the approval of the first new treatment for mesothelioma patients in England and Wales in over 14 years.

The National Institute for Health and Care Excellence (NICE) has issued a Final Appraisal Document (FAD) recommending the combination of nivolumab plus ipilimumab for the first line treatment of adult patients with unresectable malignant pleural mesothelioma (MPM) in England and Wales. Within the FAD, the NICE committee also recommended extending the guidance of nivolumab plus ipilimumab to treat rarer forms of mesothelioma found in the pericardium and peritoneum (the lining of the heart and abdomen respectively).

The nivolumab and ipilimumab combined immunotherapy treatment has been proven in CheckMate -743, a randomised, open-label, Phase 3 trial which showed improved three-year overall survival rates for the immunotherapy combination, in comparison to chemotherapy. The NICE decision follows approval for combination therapy by the Scottish Medicines Consortium earlier this year.

Liz Darlison MBE, Chief Executive Officer at Mesothelioma UK said: "Mesothelioma is a devastating and hard to treat disease with people often diagnosed at a late stage and typically facing a poor prognosis. This decision from NICE has the potential to change the outlook for patients with MPM.

"We know that asbestos exposure causes the majority of MPM cases, and it is important that we continue to raise awareness of the symptoms and risk factors. This is a significant advance in treatment which gives patients the potential to live a better quality of life with this cancer."

Nick Maskell, Professor of Respiratory Medicine at the University of Bristol and Chair of Mesothelioma UK added: "We are extremely pleased with this long-awaited decision from NICE. It is brilliant news for mesothelioma patients and their families. We look forward to integrating first line ipilimumab/ nivolumab into our treatment pathways.

"Combination immunotherapy with ipilimumab/ nivolumab has shown superiority over chemotherapy and the decision to approve this provides a new routinely available standard of care for NHS patients. This progress would not be possible without the Checkmate-743 trial and underlines the importance of clinical trials and the value of patient participation. We are very grateful to patients that enter clinical trials, which often requires them to take on the extra burden of trial visits, tests and travel, to help advance research and treatment for us all.

"I am very proud of Mesothelioma UK which has advocated unceasingly for this new treatment. We are here for anyone affected by mesothelioma and will continue to do all that we can."

Reforming the UK's asbestos management system

The DWP select committee inquiry was set up in September 2021 to review the Health and Safety Executive (HSE)`s standards for monitoring and managing asbestos in public buildings. Its final report was released on 21 April 2022, with recommendations including the creation of a national asbestos strategy to include the phased removal of asbestos from public and commercial buildings within 40 years.

The Government and Health and Safety Executive's response to this report was released on 21 July 2022 and is unfortunately, very disappointing. On the phased, prioritised removal of asbestos from at-risk buildings the Government says: 'The Government could only advocate a proactive course of action in this area if there is compelling evidence that the undoubted increase in exposure to asbestos workers that will result from active removal, possibly prematurely, is justified in terms of reducing risk of exposure to building users. At present this evidence is not there.'

This is despite recent research showing an uptick in 'secondary exposure' to asbestos, especially in older-build schools and hospitals.

According to HSE statistics released on asbestosis, mesothelioma and lung cancer in Britain, asbestos-related deaths have now climbed to over 5,000 each year. In 2020, there were 2,544 mesothelioma deaths in total, with a similar number of lung cancer deaths linked to past exposures to asbestos [1].

Nurses and teachers are now 3-5 times more likely to develop mesothelioma than the general UK population, while pupils are up to 10 times more likely to be exposed than teachers [2].

Charles Pickles, founder of the Airtight on Asbestos campaign, responds: "The recommendations put forward in the Work and Pensions report were both sensible and timely, and yet they have been almost completely rejected by Government. To put it bluntly, the UK has one of the worst asbestos legacies in the world – and our current lack of an informed strategy for dealing with this is shocking. For any project involving old buildings it will mean increased costs, delays and even untimely deaths. Industry, campaigners, patient organisations and unions are united in their disappointment of this missed opportunity."

Liz Darlison, Chief Executive Officer of Mesothelioma UK said: "The Government and the public are mistaken if they think asbestos is a problem that has already been solved. Despite the UK officially banning asbestos in 1999, it is still very much present and the risk of exposure is with us every day. We do not have a cure for mesothelioma, but it's a preventable cancer for future generations with the removal of asbestos from all our buildings.

"The Government's blunt rejection of the recommendation from the Work and Pensions Select Committee for a dedicated programme for the phased removal of asbestos in public buildings is numbing. I would like to invite those decision makers to come and spend a day with one of our nurses or attend a patient support group and explain why the Government has made a choice to not prevent future generations dying of mesothelioma. It's the asbestos that must go, not more people."

References

[1] Health and Safety Executive (HSE), 2022. 'Asbestos-related disease statistics, Great Britain 2022', pp.2. https://www.hse.gov.uk/statistics/causdis/asbestos-related-disease.pdf

[2] Howie, R., 2018. 'Mesothelioma deaths in teachers and nurses in Great Britain', Environmental Health Scotland, 29 (4), pp.35-37. P. 36.

Action Mesothelioma Day

Action Mesothelioma Day (Action Meso Day), an annual event to raise awareness of mesothelioma and the dangers of asbestos, was marked on 1 July this year by turning landmarks blue for the #GoBlueForMeso campaign.

Organised by the UK Mesothelioma Alliance (UKMA), the ActionMeso campaign saw people and organisations ask their local landmarks and buildings to light up blue and hold events to mark the occasion.

Mesothelioma UK's headquarters is in Leicester where the King Richard III Visitor Centre and the Leicester Royal Infirmary hospital turned blue for the night. The charity also held an afternoon tea to raise funds and awareness.

Guests were shown our new information video, 'What is Meso?' and heard from special guest Sandra Ball, who shared her experience of caring for her late husband. The event raised over £500.

The #GoBlueForMeso campaign was a huge success and over 100 buildings around the UK lit up blue. The message was seen over five million times on social media!

UKMA will build on this success next year for Action Meso Day 2023 and continue to raise awareness of the dangers of asbestos.

Go Blue for Meso & AMD 2022

The East of England Patient Support Group (CIO) supported Action Meso Day 2022 and 'Go Blue for Meso' over the weekend of 1-3 July. They attended events at Ely Cathedral and the Old Pack Bridge at St. Ives in Cambridgeshire, and held an Action Mesothelioma Day service at St. Edmundsbury Cathedral in Suffolk on Sunday 3 July.

Patients, carers, supporters and trustees gathered at locations across the East of England to support mesothelioma causes, and also to remember much loved volunteer, Joseph McConnell (Joe) who passed away in June, after a long illness (see Joseph's obituary below).

Joseph (Joe) McConnell obituary

We are sad to announce the passing of good friend and supporter Joseph (Joe) McConnell. Despite Joe's poor health, he was present at many fundraising and awareness events, and campaigns across the country.

Joe (with his wife Eileen and mascot dog, Herbie) began volunteering in 2015 when Brian Wallis was in the process of forming support groups across the region.

Joe and Eileen supported many events and raised a huge amount for Mesothelioma UK, mesothelioma specialist nurses, cancer research and helped to fund support groups in East Anglia.

Joe was born in Carrickfergus, Northern Ireland, and came to England in 1962. He was a qualified carpenter and completed his apprenticeship at the Harland & Wolfe shipyard in Belfast. He worked on some of the best known building projects in UK. Joe's career abruptly ended when he fell through an asbestos roof when working on a project in London in 1990s.

He leaves his wife Eileen, and extended family in Northern Ireland and in the Republic. Rest in Peace Joe – and thank you for what you did to raise awareness to the dangers of asbestos exposure in the East of England and beyond. Our sincere condolences go out to Eileen and Joe's family.

Mesothelioma National Statistics

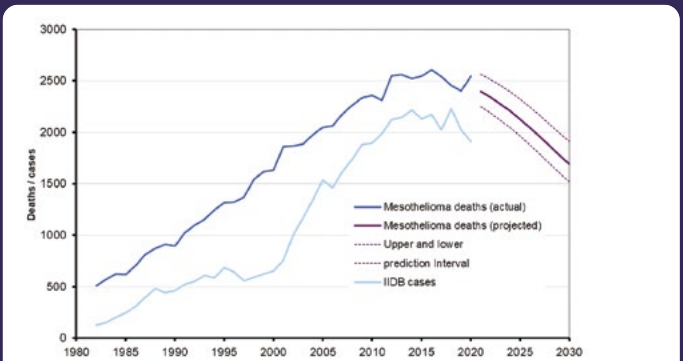


Figure 1 – Mesothelioma annual deaths, IIDB cases and projected future deaths to 2030 in GB

The Health and Safety Executive has been publishing statistics on annual mesothelioma deaths in Great Britain on a consistent basis for 50 years. Detailed statistical tables and commentary are available as part of HSE's National Statistics web pages at: www.hse.gov.uk/statistics/causdis/index.htm

The data provides a stark picture of the tragic consequences of the industrial use of asbestos which was widespread in the post war building industry as well as many other industrial settings where asbestos was widely used. By the time that the most hazardous forms of asbestos had been banned in 1980, many construction workers in particular had accrued high exposures which then led to the steep increase in mortality rates over the following decades. Britain now has among the highest mesothelioma rates in the world, similar to countries such as Australia and the Netherlands. Research shows this is likely to be because more blue and brown asbestos was used here than in other countries.

Annual numbers of mesothelioma deaths in Britain have been broadly level over the last decade with an average of over 2,500 per year. This compares with less than 200 deaths per year in the late 1960s when the data was first collected. The latest data shows that in 2020 there were 2,544 deaths. This is a rise of 6% compared with the number in 2019, but our analyses of trends – and particularly the lower rates seen among those born more recently – still suggest that annual deaths will reduce over the coming decade. Around two thirds of deaths now occur in those aged over 75 years and deaths in this age group are continuing to increase, while deaths below age 65 are decreasing. Unfortunately, part of the reason for the increase in mesothelioma deaths in 2020 compared with 2019 could be that some people who were suffering from mesothelioma may have died from COVID-19 during the first waves of the pandemic.

The majority of mesothelioma deaths are among men, though the data for women shows similar pattern of increase in deaths over the long term, with over 400 per year over the last decade and 459 in 2020. The statistics show that a much smaller proportion of the overall deaths in women worked in occupations that were most obviously associated with asbestos exposure.

Other research into asbestos fibres concentrations in samples of lung tissue obtained from collapsed lung patients also shows that exposures in the past were not confined just to those who worked with asbestos as part of their job. Such exposures are likely to account for many current cases in women, and similar absolute numbers of cases in men. This research also shows that exposures reduced rapidly during the 1970s and continued to reduce after 1980.

However, although it is now a long time since there was any new use of asbestos in Britain, clearly there is an important and ongoing need for strict controls to prevent exposures arising from asbestos where it remains present in buildings today.

IASLC 2022 world conference on lung cancer - my highlights

By Rachel Thomas, Respiratory Nurse Advisor, Asbestos Litigation at Hugh James

My role as a specialist mesothelioma nurse advisor at Hugh James solicitors is unique and gives me the opportunity to bring the skills and expertise I have learnt with many years as a Mesothelioma UK nurse to benefit the clients I assist in my role with Hugh James. I am very fortunate that this role enables me to attend many fantastic education events.

One such opportunity was the International Association for Study of Lung Cancer (IASLC) World Lung Cancer Conference in Vienna which brought together medical experts, specialist nurses and patient advocates to share new and emerging treatments in the field of lung cancer and mesothelioma.

A late notice invitation from DaSH Global enabled me to step in for Liz Darlison (CEO of Mesothelioma UK) and join Faye Forde (Director of Operations at Mesothelioma UK) to attend this conference. DaSH Global are leading on the My Health Companion patient app and this was their first World Lung Conference where they were able to showcase the app to the global mesothelioma/lung cancer community.

There was a big focus on immunotherapy and one trial that stood out for me was conducted by the Netherlands Cancer Institute looking at pembrolizumab and lenvatinib in 2nd and 3rd line malignant pleural mesothelioma patients. This was a single arm Phase II study– PEMbrolizumab Plus Lenvatanib in Second and Third Line Malignant Pleural Mesothelioma: A single Arm Phase II Study (PEMMELA).

Lenvatinib is an angiogenesis inhibitor and has previously been used in differentiated thyroid cancer, advanced kidney cancer and liver cancer. It is in the same class of drugs as bevacizumab.

Out of the 38 patients enrolled, 22 patients had a partial response, 16 had stable disease and at the time of the presentation, no patients had disease progression. The main side effects reported was fatigue, hoarseness of voice and anorexia, with serious adverse events reported in 10 patients. The conclusion from the trials team was that there was remarkable but manageable toxicity and patients could have a dose reduction.

It was fantastic to see a number of UK Lung Cancer Clinical Nurse Specialist (CNS) colleagues presenting on the main stages alongside medical professionals from across the world.

Paula Shepherd, Lung Cancer CNS looked at survivorship and financial toxicity (the harmful effect of high cost of treatment on a person's quality of life), which is not something we commonly consider in the UK due to the NHS. However, patients have other financial toxicities such as travel costs, increasing energy bills and petrol costs which can all impact on patients accessing treatment if they have to travel to a cancer centre. Paula advised that we should assess all of our patients for financial toxicity at the point of diagnosis as quality of life can be severely affected by the high cost of treatment.

Jackie Fenemore (Lung Cancer Nursing UK Chair) gave a very insightful talk on hybrid clinics and the outcome of the recent Global Lung Cancer Coalition (GLCC) survey on patient experience. The majority of patients reported that they would prefer to see their lung cancer nurse or clinician in person at certain points in their treatment pathway, such as at diagnosis, first consultation with oncologist, when treatment needs to change and when treatment options are exhausted.

'Mesothelioma Through the Looking Glass' was a highly scientific overview of the mutational profile of mesothelioma, demonstrating that not all epithelioid mesotheliomas are the same and will respond to treatment differently. There is a move towards understanding the genetic profile of mesothelioma which could really impact on the way we treat mesothelioma in the future, much like lung cancer.

One of my favourite presentations was by Lavinia Magee, Nurse Consultant at Papworth Hospital, on patient perspectives for radical management of advanced disease, focusing on treatment disparities in different groups of patients. The experience of engaged, educated and empowered patients can be very different to those from racial, ethnic minorities or hidden populations such as the homeless, trans community or those in abusive relationships. Lavinia's talk was powerful, challenging and brought the voice of many patients to the world lung cancer stage.

International Thoracic Oncology Nursing Forum had some excellent presentations, some of which I will be looking at in more detail to see how I can incorporate learning into practice.

A great conference and wonderful to see several patient advocates included as part of multidisciplinary team meeting presentations. They had their own space, and it was a vibrant and engaging space with many visitors from oncologists and nurses talking to patients. Mesothelioma UK and DaSH Global were very visible in the exhibition hall, showcasing the vital work they do for patients/carers in the UK. A huge thank you to Liz Darlison for supporting me to represent Mesothelioma UK at conference in her place and to DaSH Global for asking me to attend.

Launch of Uncovering Mesothelioma report

Mesothelioma UK is pleased to share the Uncovering Mesothelioma report, published by the pharmaceutical company Bristol Myers Squibb.

Mesothelioma patients are often diagnosed with late-stage disease and receive a poor prognosis. There is an urgent need for action to address the barriers many patients face during the diagnosis and treatment of their condition. It can often be a lengthy process to get a diagnosis due to limited awareness and symptoms overlapping with other conditions.[1]

Interviews were held with five mesothelioma patients and one carer to understand the patient experience throughout the diagnosis pathway, which identified key recommendations for improvement. Due to the small number of interviewees, the report cannot be said to represent the wider population but rather provide a snapshot of lived experience.

Recommendations are diverse, covering the onset of symptoms, presentation in primary care, diagnosis confirmation and treatment planning. Ultimately, the report suggests that changes are needed throughout the patient pathway to ensure that public awareness is raised, diagnosis is sped up, patient communications are improved, and that access to high quality treatment and care is consistent across the country.

Mesothelioma UK was invited by Bristol Myers Squibb to share our expertise in shaping this report.

To read a full copy of the report, visit www.mesothelioma.uk.com/uncovering-mesothelioma

[1]American Cancer Society (2018) Signs and Symptoms of Mesothelioma. Available at: https://www.cancer.org/cancer/malignant-mesothelioma/detection-diagnosis-staging/signs-symptoms.html [Available at 17.08.22]

CEO Liz Darlison to speak at the European Asbestos Conference

Liz Darlison

Mesothelioma UK's CEO, Liz Darlison, has been confirmed as a speaker at the European Asbestos Forum Conference (EAF). The event will take place from 10-11 November in Amsterdam, in the Netherlands, where she will deliver a talk entitled, Establishing a National Support Service for Mesothelioma Victims, on 11 November at 1.05pm (CET) (12.05pm GMT). Liz is part of the lineup of speakers for Session A, which will focus on asbestos and its impact on society. The concurrent Session B theme will revolve around asbestos and professional perspectives.

The conference is a key event for specialists around the world to come together to learn and share details and updates on scientific progress and innovations around asbestos. The event is run by the European Asbestos Forum Foundation, which aims to improve international relations and knowledge regarding all matters related to health and safety, with a focus on asbestos.

Liz commented: "I am looking forward to the opportunity to share our insights and perspectives on asbestos at the European Asbestos Forum Conference. This will help to raise awareness of the charity's work, while also offering a way to get up-to-date on the latest developments, learn from others, network with them and use these collectively, as a goal for the prevention of the disease. We're proud to be recognised as internationally-renowned experts in mesothelioma and the patient experience."

Details of the EAF Conference can be found at www.europeanasbestosforum.org

Alice – A Fight For Life

Alice Jefferson

To mark the 40th anniversary of Yorkshire Television's landmark documentary Alice - A Fight for Life, which was pivotal in raising awareness of the dangers of asbestos exposure, law firm RWK Goodman is hosting a special screening of the film on 29 September 2022.

The documentary features 47-year-old Alice Jefferson, a British woman who developed malignant pleural mesothelioma 30 years after working for nine months at Cape Industries' Acre Mill asbestos plant in Hebden Bridge, West Yorkshire. Alice died of mesothelioma in February 1982, a month after filming for the programme had ended.

The screening will take place at Hebden Bridge Picture House, West Yorkshire and coincides with the protest against Cape Industries taking place in Rotherham and Warrington on 30 September 2022.

Proceeds from the event are going to asbestos support groups and charities including Mesothelioma UK. Book your place on Eventbrite at www.eventbrite.co.uk/e/charity-screening-of-alice-a-fight-for-life-tickets-332928617457

Patient and Carer Day 2022

We're delighted that our Patient and Carer Day will be in person this year and will take place from 9am to 4pm on Thursday 6 October at the Belfry Hotel, Nottingham. The event will be followed by our annual awards evening.

The day is a chance to learn, share and meet others with similar experiences. Learn about the latest on mesothelioma clinical trials, treatments and research from clinical experts, and hear personal stories from patients. There will be three question and answer panel sessions with the speakers on the day.

The agenda for the day includes a clinical trials update, presentations on radiotherapy and immunotherapy, updates on the national peritoneal service and the Mesothelioma UK Research Centre, a talk on accessing non-NHS treatments, and sessions on health and wellbeing.

This event now sold out but we do have sponsorship opportunities available. For more information, email rachel.owen@mesothelioma.uk.com

Following the Patient and Carer Day, we will be hosting our awards night. Awards will be presented for Fundraiser of the Year, Junior Fundraiser of the Year, Corporate Sponsor of the year, Most Inspirational Fundraiser, Special Contribution and also the Impact Award.

Clydebank Asbestos Group 30th anniversary event

Join the Golden Jubilee Conference Hotel on 14 October 2022 to mark 30 years of Clydebank Asbestos Group. Please register for your place on Eventbrite at www.eventbrite.co.uk/e/clyde-bank-asbestos-group-30th-anniversary-event-tick-ets-395921902067

Join our Asbestos Commercial Club

If you are a business involved in the management of asbestos or the diseases it causes, why not join our Asbestos Commercial Club (MUKACC) to support the vital work that we do?

Joining MUKACC can be a great morale booster for your staff, encouraging them to get involved and it will give both them and you that much-needed feel good factor of helping others and the recognition of supporting a good cause.

Your monthly contribution will make a huge difference to those living with mesothelioma and being an associate of Mesothelioma UK is a fantastic way of joining a network of like-minded organisations, all striving for the same cause.

For a minimum donation of just £10 per month, you will be part of a select group receiving various benefits:

- Your company logo on the MUKACC area of our website
- An opportunity to include an article in our quarterly Mesothelioma Matters magazine
- Receive our bi-monthly E-Asbestos News, which will keep you up to date on what is happening in the mesothelioma community
- Early notification and access to tickets for various events throughout the year
- A MUKACC membership certificate to be displayed in your office

It's about getting involved and with time limitations for all in this busy industry, what could be easier?

We would love the opportunity to work with you.

If you would like to join the club, or require further information, please contact:
corporate@mesothelioma.uk.com

Introducing the new Health Companion portal

Working in collaboration with DaSH-Global, a pharmaceutical manufacturing company, we have developed a new digital patient portal known as the 'Health Companion'. The new system will allow patients to submit data regarding their quality of life and experiences in the management of mesothelioma as well as any costs associated with the condition.

Patients will be able to take greater control in managing their mesothelioma with the capability to record, monitor and communicate healthcare information, and help to improve the interaction and outcomes they have with healthcare services.

The data collected from the Health Companion will provide evidence to support better targeting of services whilst enhancing nurse-patient communications. Health Companion managers will also be available to support the patients directly or via communications with the clinical nurse.

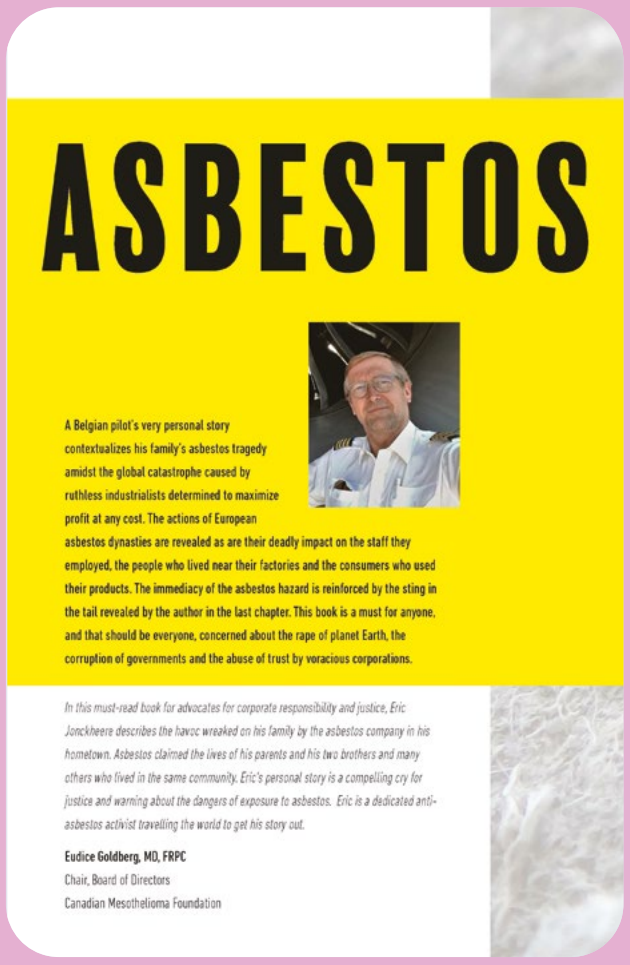
Details on the new portal can be found at www.health-companion.me

For more information on how you can get involved, contact the Health Companion Managers by email at hcmanager@mesothelioma.uk.com or you can call 0116 218 5718.

Book review

By Lorraine Creech (former UK Head of Nursing at Mesothelioma UK)

Asbestos: My War With The Devil's Dust by Eric Jonckheere



This is a very personal mesothelioma story of Eric Jonckheere's family tragedy, resulting from exposure to asbestos. Eric, a Belgian pilot and brave mesothelioma activist captivates the reader with detail from what appeared to be his perfect childhood living in Kapelle-op-den-Bos where his father was an engineer at the Eternit asbestos cement manufacturing plant.

The dreadful story unfolds of his father's death and occupational exposure to asbestos. His mother and two brothers died of mesothelioma and Eric was diagnosed with the disease last year. Eric is one of five brothers and the oldest surviving son. He describes in the book how the sword of Damocles has hung over him, the devastation of their family life and the strife required not only to receive justice and compensation, but to deliver the awareness of this global catastrophe caused by ruthless industrialists.

I found the book enthralling and a compelling read. Every word portrays emotion entwined with knowledge and personal life experience of this very close-knit family as time after time they have fought the battle with mesothelioma. Eric's mother described mesothelioma as the 'octopus' and visualisation such as this persists throughout the book in Eric's extremely eloquent writing.

I feel privileged to have met Eric. I wish him well and recommend this must-read book for everyone. The book can be bought via Yvonne Waterman (acting as publisher for Eric). Contact Yvonne at waterman@watermanlegal.nl

A limited number of copies are available and proceeds after costs will support Eric in his court case against Eternit. People can set their own price (within reason), with all kind offers considered.

CLASAG: make connections, get help

Mesothelioma UK is proud of the strong relationships that we have built with various support groups. Patients who are coping with mesothelioma and facing stressful life changes, do not have to go it alone - a support group can help.

The Cumbria and Lancashire Asbestos Support Advice Group (CLASAG) started online meetings in July and now convenes every third Monday of each month from 1-3pm in Barrow-in-Furness. CLASAG has also launched a new group in Preston which meets in person every fourth Monday at the Preston Disability Information Services Centre from 1-3pm. This brings the total number of regional support groups in northwest England to two.

CLASAG provides an opportunity for people to share personal experiences and feelings, coping strategies or first-hand information about living with mesothelioma and the treatments they have had.

Sandra Wilson, who coordinates the meetings said: "It's really important for people to come together to gain support, help and guidance, but these support groups are also where many of our members have made lifelong friends."

The meetings feature someone who shares the group's common experience and every one in four sessions is led by a professional facilitator, such as a lung cancer nurse specialist, a dietitian, complementary therapy specialist, or cancer and palliative care professional.

Residents in Cumbria and Lancashire who have an asbestos-related condition and their carers are welcome to join the meetings. For further information on CLASAG, please contact admin@disabilityfirst.org or call either 01253 472201 or 01253 472202.

Publications

Mesothelioma UK is delighted to include this regular addition to Mesothelioma Matters. In each edition any new publications in the preceding three months, the title, author and journal, will be listed. We hope you find this useful and thank you UHL clinical librarians!

UHL Clinical Librarian Service
"bringing you the evidence"

New scientific research

Understanding clinical decision-making in mesothelioma care: a mixed methods study. Henshall C, Dawson P, Rahman N, Ball H, Sundralingam A, Shahidi M, McKeown E, Park J, Walthall H, Davey Z.BMJ Open Respir Res. 2022 Jul;9(1):e001312. doi: 10.1136/bmjresp-2022-001312.

Pleural mesothelioma risk by industry and occupation: results from the Multicentre Italian Study on the Etiology of Mesothelioma (MISEM).
Migliore E, Consonni D, Peters S, Vermeulen RCH, Kromhout H, Baldassarre A, Cavone D, Chellini E, Magnani C, Mensi C, Merler E, Musti M, Marinaccio A, Mirabelli D.
Environ Health. 2022 Jun 18;21(1):60. doi: 10.1186/s12940-022-00869-5.

Localized Malignant Peritoneal Mesothelioma (LMPeM) in Women: A Clinicopathologic Study of 18 Cases.
Malpica A, Euscher ED, Marques-Piubelli ML, Miranda RN, Raghav KP, Fournier KF, Ramalingam P.
Am J Surg Pathol. 2022 Jun 20. doi: 10.1097/PAS.0000000000001924. Online ahead of print.

Australasian Malignant PLeural Effusion (AMPLE)-3 trial: study protocol for a multi-centre randomised study comparing indwelling pleural catheter (±talc pleurodesis) versus video-assisted thoracoscopic surgery for management of malignant pleural effusion.
Fitzgerald DB, Sidhu C, Budgeon C, Tan AL, Read CA, Kwan BCH, Smith NA, Fysh ET, Muruganandan S, Saghaie T, Shrestha R, Badiei A, Nguyen P, Burke A, Goddard J, Windsor M, McDonald J, Wright G, Czarnecka K, Sivakumar P, Yasufuku K, Feller-Kopman DJ, Maskell NA, Murray K, Lee YCG.
Trials. 2022 Jun 27;23(1):530. doi: 10.1186/s13063-022-06405-7.

Second Surgery for Recurrent Malignant Pleural Mesothelioma after Multimodality Treatment: A Systematic Review.
Bellini A, Mazzarra S, Sterrantino S, Argnani D, Stella F.
J Clin Med. 2022 Jun 10;11(12):3340. doi: 10.3390/jcm11123340.

A prognostic score for patients with malignant pleural mesothelioma (MPM) receiving second-line immunotherapy or chemotherapy in the ETOP 9-15 PROMISE-meso phase III trial.
Luigi Banna G, Addeo A, Zygoura P, Tsourti Z, Popat S, Curioni-Fontecedro A, Nadal E, Shah R, Pope A, Fisher P, Spicer J, Roy A, Gilligan D, Gautschi O, Janthur WD, López-Castro R, Roschitzki-Voser H, Dafni U, Peters S, Stahel RA.
Lung Cancer. 2022 Jul;169:77-83. doi: 10.1016/j.lungcan.2022.05.018. Epub 2022 May 28.

Society for Immunotherapy of Cancer (SITC) clinical practice guideline on immunotherapy for the treatment of lung cancer and mesothelioma.
Govindan R, Aggarwal C, Antonia SJ, Davies M, Dubinett SM, Ferris A, Forde PM, Garon EB, Goldberg SB, Hassan R, Hellmann MD, Hirsch FR, Johnson ML, Malik S, Morgensztern D, Neal JW, Patel JD, Rimm DL, Sagorsky S, Schwartz LH, Sepesi B, Herbst RS.
J Immunother Cancer. 2022 May;10(5):e003956. doi: 10.1136/jitc-2021-003956.

Multimodal Treatment of Malignant Pleural Mesothelioma: Real-World Experience with 112 Patients.
Holzknecht A, Illini O, Hochmair MJ, Krenbek D, Setinek U, Huemer F, Bitterlich E, Kaindl C, Getman V, Akan A, Weber M, Leobacher G, Valipour A, Mueller MR, Watzka SB.
Cancers (Basel). 2022 Apr 30;14(9):2245. doi: 10.3390/cancers14092245.

First-line nivolumab plus ipilimumab versus chemotherapy for the treatment of unresectable malignant pleural mesothelioma: patient-reported outcomes in CheckMate 743.
Scherpereel A, Antonia S, Bautista Y, Grossi F, Kowalski D, Zalcman G, Nowak AK, Fujimoto N, Peters S, Tsao AS, Mansfield AS, Popat S, Sun X, Lawrance R, Zhang X, Daumont MJ, Bennett B, McKenna M, Baas P.
Lung Cancer. 2022 May;167:8-16. doi: 10.1016/j.**lungcan.2022.03.012. Epub 2022 Mar 21.**

Qualitative studies and patient experience

Dying of mesothelioma: A qualitative exploration of caregiver experiences.
Lee JT, Mittal DL, Warby A, Kao S, Dhillon HM, Vardy JL.
Eur J Cancer Care (Engl). 2022 Jun 20:e13627. doi: 10.1111/ecc.13627. Online ahead of print.

Living with mesothelioma: A systematic review of patient and caregiver psychosocial support needs.
Breen LJ, Huseini T, Same A, Peddle-McIntyre CJ, Lee YCG.
Patient Educ Couns. 2022 Jul;105(7):1904-1916. doi: 10.1016/j.pec.2022.02.017. Epub 2022 Feb 26.

Living beyond expectations: a qualitative study into the experience of long-term survivors with pleural mesothelioma and their carers.
Johnson M, Allmark P, Tod A.
BMJ Open Respir Res. 2022 May;9(1):e001252. doi: 10.1136/bmjresp-2022-001252.

Please contact your own clinical library or view the journals webpages to seek access to the full publications

CLINICAL TRIALS

Targeted cancer treatment could provide new hope for mesothelioma patients

Researchers at the Cancer Research UK Southampton Clinical Trials Unit and the University of Leicester are running the NERO trial (Niraparib Efficacy in patients with unResectable MesotheliOma) to test whether a type of drug called a PARP inhibitor could be an effective treatment for mesothelioma patients.

PARP inhibitors have already been shown to improve the survival of patients with breast and ovarian cancers that carry specific mutations. They work by blocking a protein which helps to repair damaged DNA in cancer cells, thereby causing the cancer cells to die.

Professor Gareth Griffiths, Director of the Southampton Clinical Trials Unit said: "There is an urgent need to explore more effective approaches and different therapies for this aggressive form of cancer.

"We recently published the results of the CONFIRM trial, the first study of its kind to show that an immunotherapy treatment improved survival for patients with mesothelioma. This was a huge breakthrough and immunotherapy has now been included in European treatment guidelines for mesothelioma. But if patients fail on standards of care and treatment, mesothelioma remains an incurable disease and therefore further research into other treatment options, in addition to just active symptom control, is desperately needed."

Mesothelioma patients whose tumours have progressed following chemotherapy and are therefore more likely to be susceptible to a PARP inhibitor will be invited to join the NERO trial where they will be given a drug called niraparib.

Dean Fennell, Professor of Thoracic Medical Oncology at the University of Leicester and Chief Investigator of the NERO trial, says: "In a previous, small study called the MiST1 trial, we showed that mesothelioma does respond to this type of drug, but further investigation is needed to test whether PARP inhibitors could be a new treatment option for patients. If the NERO trial is positive, this study will lead to the approval of a new medicine for use around the world, one that would extend the life expectancy of patients following initial chemotherapy."

NERO will recruit 84 patients who have already had chemotherapy treatment at hospitals across the UK. Patients will be randomly allocated into one of two arms within the trial, with a 2:1 chance of receiving niraparib so that the researchers can compare the effect of the drug on the tumour. Those patients who do not receive niraparib will be closely monitored for signs of early tumour growth so that they can go on to receive an alternative treatment if necessary.

NERO is funded by Asthma and Lung UK and developed in collaboration with Mesothelioma UK, with additional support from Cancer Research UK core funding at the Southampton Clinical Trials Unit.

For details on the NERO trial, visit www.southampton.ac.uk/ctu/trialportfolio/listoftrials/nero.page.

Details on the CONFIRM trial can be found at www.thelancet.com/journals/lanonc/article/PIIS1470-2045(21)00471-X/fulltext

Details of the MiST1 trial can be found at www.thelancet.com/journals/lanres/article/PIIS2213-2600(20)30390-8/fulltext

Accessing the clinical trials app

Mesothelioma UK's Clinical Trials App is a universal mobile app for trial participants that makes their involvement in clinical studies more convenient. The app, available on Apple's App Store and Google Play, is intended to be a flexible option to offer patients the choice of participating in clinical studies.

The app supersedes the previous clinical trials tables which were featured on the Mesothelioma UK website and in the quarterly magazine.

The app provides general information about trials including different types and phases, things to consider before joining a trial and how to join.

Patients can then search for a trial which is suitable for their type and stage of mesothelioma.

The app will tell patients everything they need to know including eligibility and exclusion criteria, treatment schedule, location and contact information.

ASSESS-Meso update

By Dr Anna Bibby, CI for ASSESS-meso

ASSESS-meso is a prospective observational cohort study examining the natural history of mesothelioma, exploring potential biomarkers and factors that may predict outcome, as well as providing a resource for future trials within a cohort.

ASSESS-meso has just recruited its 300th participant! This is excellent progress towards our target of 700, and represents a really impressive bounce back from the challenges and delays caused by the COVID pandemic. We currently have 17 sites actively recruiting, with five additional interested sites aiming to open in the next quarter.

We have submitted the protocol for publication, and a second manuscript reporting a (pre-specified) interim analysis of participant characteristics is under review. The latter paper shows that the ASSESS-meso study population is much more similar to real-world mesothelioma patients than previous clinical trials, and confirms that we are meeting our goal to create a representative cohort, as well as achieving our aim to widen research availability and inclusivity to groups who were excluded from previous research.

We have several sub-studies underway within ASSESS-meso, including the British Lung Foundation funded pain sub-study (PI Dr Catriona Mayland), the Mesothelioma UK funded MINNOW study (PI Dr Stephanie Ejegi-Memeh) and the Mesothelioma UK pleural fluid genomics study (PI Dr Beth Sage). We are also working with collaborators at the University of British Columbia in Canada looking at circulating tumour DNA in blood samples (PI Dr Stephane Le Bihan), further genomic profiling with the Beatson Institute in Glasgow (PI Prof Daniel Murphy) and our ongoing productive relationship with the Cancer Research UK-funded PREDICT-meso network (PI Prof Kevin Blyth).

Over the next few years, we aim to maintain our current rate of recruitment as well as completing and publishing the results of the various sub-studies underway. In the meantime, we are always open to receiving ideas, suggestions or proposals for further collaborations or sub-studies from anyone across the mesothelioma community.

Thanks to all members of the team for your hard work so far, and to all participants and relatives who are helping advance our understanding of this disease.

HIT-Meso

Mesothelioma UK is delighted that the first ever UK study in proton beam therapy for mesothelioma has secured funding and will open soon. Here's more about the HIT-Meso study.

Study focus
Pleural mesothelioma is cancer which begins in the tissues lining the lungs. There are limited treatments and survival rates are low. Conventional photon radiotherapy is not routinely used for mesothelioma because the amount of lung tissue required to be treated with radiation is large (half of the chest). This would lead to a high rate of side effects, which may be severe. Where photon radiotherapy has been used for other lung cancers (smaller areas), it has been shown in previous studies to help people who are treated with it to live longer.

Proton therapy is a type of radiotherapy which results in less radiation to healthy tissues surrounding the cancer compared to photon radiotherapy. It is now first choice over photon radiotherapy for many cancers in children / young adults, and for those patients who have tumours very close to parts of the body where radiation may be harmful such as the spinal cord. Using proton therapy for mesothelioma would greatly reduce radiation to the heart, other lung and other nearby organs like the oesophagus (which is why side effect rates are high with photon radiotherapy). This trial aims to use proton radiotherapy for patients with mesothelioma of the lung lining to improve overall survival and maintain a better quality of life for longer.

All patients with mesothelioma of the lining of one lung will be considered for the trial. If they meet the eligibility criteria, they will be randomly allocated to receive either the proton radiation, or, the current standard of care for mesothelioma, which are; chemotherapy, photon radiation to small areas for symptom control or monitoring. The proton radiation will be delivered daily (Monday-Friday) over five weeks at the proton centre in London or Manchester. The trial aims to recruit 148 patients in total.

Practical implications
The aim of the trial is to produce high quality evidence for the use of proton beam radiation therapy to treat patients with mesothelioma of the lung.

Mesothelioma is a type of cancer for which life expectancy rates remain low and advances in treatment are desperately needed. Research into treatment with radiation therapy is lacking due to the potential side effects associated with it. Using proton therapy to limit these side effects would provide an invaluable way to improve outcomes and life expectancy for these patients whilst maintaining their quality of life.

Currently, the UK proton beam facilities have capacity to treat patients on research trials and while available, this should be utilised. The production of high-quality evidence from this national trial will allow the national guidance on best available treatments for mesothelioma to be updated, and further patients to benefit from this in the future (the incidence of mesothelioma due to asbestos is forecast to remain high for many years). It may delay the need for further cancer treatments for these patients, such as chemotherapy, which can impact on their day-to-day function.

Additionally, once the role of proton therapy has become established as a new routine treatment, it will allow further trials to be developed which build on this either by 'boosting' the amount of radiation given to see if it improves life expectancy further, or by combining the radiation therapy with other treatments (such as immune therapy).

MITOPE clinical trial brings a new treatment to patients suffering from Malignant Pleural Effusion and Malignant Mesothelioma

15% of cancer patients develop pleural effusion as their disease spreads to the lungs and accumulates excess fluid. This condition is common among mesothelioma patients. Earlier this year, RS Oncology, LLC, a US-based biotechnical company focused on the treatment of patients with malignant pleural effusion (MPE) and mesothelioma, initiated its MITOPE clinical trial, a first-in-human Phase 1/2 clinical trial in the UK.

This clinical trial offers a new treatment option for MPE and mesothelioma patients using RS Oncology's novel drug known as RSO-021. This new drug targets a specific mitochondrial enzyme (PRX3) by regulating oxidative stress to eliminate cancer cells while sparing normal cells. RSO-021 is administered weekly locally into the pleural cavity using an intrapleural catheter immediately after the pleural effusion is drained.

This clinical trial is open and available to patients who are at least 18 years old, suffering from MPE and/or mesothelioma, and have documented tumor progression after receiving at least one prior standard of care treatment.

The MITOPE trial is currently offered at the University Hospitals of Leicester (UHL) and at Oxford University Hospital with additional sites set to open in the near term across the UK.

"We're excited to see the MITOPE trial open for the recruitment of patients and the continued treatment of the first two patients with RSO-021, our novel metabolic therapy. This trial is an important step in improving treatment for people living with this aggressive cancer," said Jarrett Duncan, RS Oncology's CEO.

"We believe that RSO-021 works by selectively attacking a fundamental process needed for cancer growth. We hope that this novel therapeutic approach will help not only mesothelioma patients, but cancer patients of various types," added COO and Head of Business Development, George Naumov, Ph.D.

"Mesothelioma remains a lethal cancer lacking effective treatments, particularly in patients with relapsed disease. This exciting study of a first in class PRX3 inhibitor is anticipated to show promising signals that could lead to development of a new approach to tackle this cancer," said the clinical investigator from UHL, Dean Fennell, MD, Ph.D.

For more information, visit clinicaltrials.gov NCT05278975, www.mesothelioma.uk.com/clinical-trials/ or email MITOPE@rsoncology.com

The study is supported by NIHR.

LEGAL PANEL

Secondary asbestos exposure: A family fights for justice

By Phillip Gower, Director of Novum Law and specialist asbestos disease solicitor from the Cardiff office

Phillip Gower

Sadly, secondary exposure to asbestos continues to claim the lives of unsuspecting wives of men who worked in industries where asbestos-containing materials were commonly used.

Little did they know that their daily ritual of shaking the dust from their husband's overalls, jackets and work boots would result in them being diagnosed with a severe asbestos-related disease such as mesothelioma decades later.

Unfortunately, because mesothelioma takes a long time to develop, the disease has presented difficulties for the courts over the years - and continues to be a challenge.

MW's story
I am helping a family who tragically lost their mother (MW) after being diagnosed with mesothelioma. She had been exposed to asbestos between 1966 and 1984 due to her husband's work as an insulation engineer and lagger with Kitsons Insulation Limited.

MW's husband had been responsible for mixing up the asbestos insulation that was applied as lagging to the pipework. He was also involved in removing damaged asbestos lagging on industrial sites.

At the end of his working day, his overalls and hands would be covered in asbestos dust. He would hand the dirty work overalls to his wife to be washed, and she would shake them out in the garden and then wash them, then use a hand brush to sweep up any dust left lying on the floor.

Fast forward to 2017 and following the loss of her husband to asbestos-related lung cancer, MW started to lose weight and struggle with breathing. She was diagnosed with mesothelioma and sadly died not long afterwards.

Family to challenge Riverstone Insurance
We helped the family to make a mesothelioma claim against Kitsons which was successful, and the family were awarded damages in excess of £100K.

However, while Riverstone Insurance, the firm's insurers, confirm they have a policy that covers the relevant period of employment, they argue the policy does not engage because MW's mesothelioma occurred many years after her asbestos exposure.

'Trigger litigation'
Fortunately, as the result of previous court cases dealing with employers' liability policies, often referred to by lawyers as 'trigger litigation', the law should be in the family's favour.

The Supreme Court has provided guidance that 'asbestos injuries' occur at the time of exposure. This means that Riverstone should engage and meet the family's claim for damages and that they should be properly compensated.

The decision by the Supreme Court only relates to employers' liability policies and does not extend to public liability insurance. I am helping the family to extend that decision so that it applies to situations where the victim of exposure was not employed by the organisation that exposed them. We remain of the view, as does our senior barrister, that the earlier interpretation for employers' liability claims should be extended to public liability cases and that wives and daughters affected by secondary asbestos exposure should be compensated.

If we are successful, the case is likely to have significant wider implications for secondary exposure claims often covered by public liability policies.

Anecdotal evidence tells us that public liability mesothelioma claims and insurance cover is a real and serious problem with people not being compensated as insurers decide their policies do not cover these claims and side step paying compensation.

We will continue to fight to help all family members affected by asbestos diseases through no fault of their own.

Thompsons Solicitors supports young father of two

Amanda Jones, a partner and asbestos specialist at Thompsons Solicitors' Cardiff and Llanelli offices, talks about the tragic case of Jason Williams – who was only 45 when he died as a result of mesothelioma.

Amanda Jones

Jason Williams, a father of two teenage children and member of the Unite union, died in October 2019, just months after being diagnosed with mesothelioma.

Mr Williams worked for Cap Gemini at Tata Steel in Port Talbot for 10 years after completing an IT degree at Swansea University.

When he was only in his early twenties, he was exposed to asbestos while the Financial Shared Services building was undergoing maintenance work and later being refurbished.

Even when asbestos had been identified in the building and a section tented off with polythene, Jason continued to be exposed as the polythene sheeting was not adequately sealed and would flap open, meaning Jason continued to be exposed to asbestos at work during this time. He stopped working altogether due to illness in January 2019, and was diagnosed with a peritoneal mesothelioma in March 2019.

Roy, Mr Williams' father, said: "When Jason was initially seen by the hospital, they thought his symptoms were caused by Crohn's disease. However, further investigations showed he had a peritoneal mesothelioma - an awful disease which caused him to lose all his independence.

"Our family was aware of asbestos and the dangers it posed, but – like many – thought it was a problem from yesteryear.

"We could not believe that, decades after the asbestos ban came into force, Jason and his colleagues would be put in harm's way like this."

Prior to his death, Mr Williams contacted Unite Legal Services for legal support. The case continued after he died and the legal experts were able to help the family secure compensation.

His father added: "Amanda Jones from Thompsons Solicitors was absolutely superb. Along with the barrister, Mr Brace, they visited Jason at home and in hospital, and kept us updated every step of the way."

Any asbestos death is one too many, but Jason's story specifically highlights a wider issue - the continued presence of asbestos in buildings across the UK. Just because asbestos was banned in 1999, the impact of the substance is far from a thing of the past. We fear that we'll see yet more examples of younger people, women and white-collar workers dying prematurely as a result of asbestos exposure, due to a lackadaisical approach from many employers to the containment and removal of asbestos from workplaces.

Sadly, the Government does not appear to share our concerns, recently dismissing the DWP Inquiry into HSE asbestos management. This will be a green light for more half-baked, under-resourced businesses, with the result being more unnecessary deaths.

Letting lethal asbestos sit dormant in workplaces, schools, hospitals and other public buildings is not a long-term solution, so the onus must be on those responsible – whether that be employers or governments – to redouble efforts for the proper identification, containment and removal of all asbestos in buildings across the UK.

Accessing mesothelioma treatment: is the law on your side?

By Heetasha Khosla, Assistant Solicitor at Leigh Day

Heetasha Khosla

Treatment for mesothelioma is an evolving area of medicine and developments in research have meant many potential new treatments being advanced in recent years. Despite that, the options available to mesothelioma patients on the NHS remain limited and many are using legal claims to try to open the door to access alternatives.

On 14 July 2022 NICE finally approved the use of combination immunotherapy, nivolumab and ipilimumab, as first line treatment for adults diagnosed with unresectable malignant pleural mesothelioma. The Checkmate 743 clinical trial proved Ipi/Nivo more effective than chemotherapy, with 8% more people surviving after three years, and 13% showing no cancer progression in the same time period.

Life extending treatments are of vital importance and the NICE approval is welcome news, but this is the first new mesothelioma treatment to be approved in 14 years and given the NICE process for approving Ipi/Nivo lasted nearly three years in itself, mesothelioma patients cannot wait.

Clinical trials present an alternative and are a crucial part of the research process (as Checkmate 743 demonstrates). Mesothelioma UK provides updated information via their clinical trials app (see page 16 of this magazine or online at www.mesothelioma.uk.com/clinical-trials/). However, not everyone can be accepted onto trials and by their very nature, trials involve an element of uncertainty, where participants may be prescribed existing standard treatments to compare with new treatments, or may be randomly selected to have, or not to have, surgery.

When treatment is not licenced in the UK, patients can pay privately, but the cost is often substantial and typically prohibitive to most. Given that many patients developed mesothelioma from negligent exposure to asbestos and have claims for compensation, recovering private treatment costs has become a key element in legal claims to enable access to new treatment options.

The High Court in London has an 'Asbestos List' designed to fast-track mesothelioma claims and provide early interim payments in cases where a defendant is found liable, which can be used to pay for treatment and other needs while a case is ongoing.

For those who might want to explore treatment after their claim has concluded, but do not know how much it will cost, agreement can often be reached to ensure the defendant continues paying treatment costs for as long as is needed, providing freedom of choice into the future.

Legal claims are not an answer to everything; those who have a claim need to prove their treatment costs are 'reasonable' although with supportive evidence, a court is unlikely to find that potentially life-extending treatment is unreasonable. But each case is different, with some moving faster than others and funds becoming available more quickly for some.

In an ideal world, access to treatment should not be determined by those who have financial resources, but until we reach a time where we can ensure full access to treatment for all mesothelioma sufferers, legal claims may give new options to those who previously had none.

RESEARCH

Poster Prizes for Research Centre

The Mesothelioma UK Research Centre (MURC) at the University of Sheffield has been recognised for its work at national conferences.

Dr Sarah Hargreaves with her poster prize certificate.

In May, at the Lung Cancer Nursing UK annual conference, Dr Sarah Hargreaves' research project on the impact of COVID-19 on mesothelioma and lung cancer nurses won the best poster prize. The project was funded by Mesothelioma UK and captured the experiences of mesothelioma and lung cancer nurses during the second wave of the pandemic. The findings explored nurses' experiences of virtual working, impacts on workload, quality of care, and the health and wellbeing of nurses.

In July, MURC also won the runner up poster prize at the British Thoracic Oncology Group's summer meeting. This project, led by Dr Clare Gardiner is titled *Patient and public involvement (PPI) in Mesothelioma research* and is a dedicated patient and public involvement panel to ensure MURC's research is in line with the needs and priorities of patients and their families.

Congratulations to the team at MURC for its continued dedication to research that benefits the care of people diagnosed with mesothelioma, and informs mesothelioma policy and practice to improve patient experience.

New research to study the impact of cough on pleural mesothelioma patients

A new study is about to be launched which will examine cough and its impact on the quality of life for patients with pleural mesothelioma (PM). The research project, headed up by Kate Slaven of Mesothelioma UK, a Lung Cancer Clinical Nurse Specialist based at the Royal Papworth Hospital NHS Foundation Trust, will run for a year and aims to offer greater insights into the experience of cough in patients with PM and the impact it may have on their quality of life, as well as on their carers.

Pleural mesothelioma is a progressive and incurable rare cancer with a poor prognosis. Every year, over 2,700 people are diagnosed with the disease in the UK. The symptom burden may be significantly distressing and complex. Effective and timely symptom control is crucial given the poor prognosis for patients with PM. Therefore, gaining fast and effective symptom control is paramount.

To lay the groundwork for the study, members of the local mesothelioma support group who developed a cough were asked a series of questions to determine if 'cough' was a subject in need of research. The group members felt that cough is a symptom that is overlooked by healthcare professionals, who tend to focus on breathlessness and pain as a priority.

Cough is debilitating and tends to disrupt patients' quality of life and can lead to embarrassment, exhaustion and fear. In addition, its unpredictable nature causes distress and group members reported that their families feel irritated by the cough. The group reached a consensus that cough is worthy of further exploration.

The study will involve up to 15 people and will be advertised by Lung Cancer Nursing UK (LCNUK) and on the Mesothelioma UK website, its Facebook page and Twitter feed. All Mesothelioma UK nurses will be approached to support the study by identifying PM patients with a cough and their carers who may be interested in taking part.

Kate said: "I wanted to do the study because I had met several patients in the clinic who were otherwise well except for a troublesome cough and I felt that I had little to offer them. The long term goal after this initial exploratory study is to establish the most effective ways to manage the symptom and to develop guidelines for cough management for people with PM."

APPOINTMENTS

Charities collaborate to fund clinical nurse specialists around the country

Mesothelioma UK funds over 30 clinical nurse specialists around the country and partners with organisations such as those mentioned below to fund some of these posts.

East Anglia

The Mavis Nye Foundation will pick up the funding of Kate Slaven's post as a Mesothelioma UK clinical nurse specialist, based at Royal Papworth Hospital in Cambridge.

Kate Slaven

Mavis Nye, who is living with mesothelioma, set up her foundation to inspire people with the asbestos-related, terminal cancer.

Mesothelioma UK is very grateful for the support from the Mavis Nye Foundation, that will fund Kate's post which has been based at Royal Papworth Hospital for several years, and provide patients in the East of England Cancer Alliance region with a clinical nurse specialist – a vital resource for people with this disease.

Kate, who has been a nurse for over 30 years, has regional responsibility for supporting, signposting, diagnostics, treatment, and generally offering clinical support with everything relevant to mesothelioma.

Kate collaborates with colleagues across the region to promote equitable access to mesothelioma specific support and treatment throughout the region. Kate also focuses on promoting the activities of Papworth Mesothelioma Social Group and raising awareness of clinical trials.

Dr. Mavis Nye (Hon) BEM BCA., CEO of the Mavis Nye Foundation added: "I am delighted that the Foundation are able to support another nurse post for Mesothelioma UK who do so much to support patients with this terrible disease which can and should be preventable.

"Without these key nurses, patients would not benefit from the specialist care they need at such a difficult time following diagnosis. Mesothelioma UK and the Mavis Nye Foundation have a shared goal of providing care, support and hope for patients both now and for their future."

East Kent

Toni Fleming

The London Asbestos Support Awareness Group has confirmed that it will fund Toni Fleming's post as a Mesothelioma UK clinical nurse specialist, based at the Kent and Canterbury Hospital.

By providing funding for Toni's post for the next two years and with a view to funding beyond that period, London Asbestos Support Awareness Group's support enables Mesothelioma UK to continue providing patients in the Kent and Medway Cancer Alliance region with a clinical nurse specialist.

Toni, who has been a lung cancer/palliative care specialist nurse since 2004 years and a Mesothelioma UK nurse since June 2020, provides clinical care for patients and will also support the teams of healthcare professionals throughout East Kent, helping to optimise patient access to treatments and promoting clinical trials.

Toni commented: "East Kent has a particularly high proportion of mesothelioma patients so I am very grateful to London Asbestos Support Awareness Group for continuing the funding of my Mesothelioma UK post so I can continue to support patients in Kent and Medway."

London Asbestos Support Awareness Group Support Manager, Jodie Bull commented: "London Asbestos Support Awareness Group is absolutely delighted to have the opportunity to fund the Kent and Medway Cancer Alliance nursing post as we feel it provides a crucial link for sufferers of mesothelioma and other asbestos related diseases where they will be supported throughout their journey by our excellent support workers."

Leah Taylor, Mesothelioma UK Head of Nursing added: "Mesothelioma UK is so grateful to London Asbestos Support Awareness Group for providing funding for Toni's post. Collaborating with other charities like London Asbestos Support Awareness Group, with whom we share goals and aims, means that our charities can help even more mesothelioma patients and their families. We're delighted that Toni will continue to be an invaluable source of information and support to patients, families, and also to her healthcare colleagues in the Kent and Medway Cancer Alliance area."

South East

Louise Gilham

HASAG and the Mavis Nye Foundation will fund Louise Gilham's post as a Mesothelioma UK clinical nurse specialist, based at Maidstone Hospital and Tunbridge Wells Hospital/ Kent Oncology Centre.

Louise, who has been a nurse for almost 35 years and a Mesothelioma UK nurse at Maidstone and Tunbridge Wells NHS Trust/Kent Oncology Centre for five years, provides clinical care for patients and will also support the teams of healthcare professionals throughout Kent helping to optimise patient access to treatments and promoting clinical trials.

Lynne Squibb co-founder of HASAG commented: "HASAG is so proud to part fund five Mesothelioma UK nurses across the region, the newest addition being Louise Gilham's post at Maidstone and Tunbridge Wells Hospital/Kent Oncology Centre. This post is in partnership with The Mavis Nye Foundation who we are delighted to work with.

"Louise has attended HASAG's East Sussex coffee mornings since they started, providing specialist support and advice for those who attend. We are so pleased that we will continue to work closely with Louise and her team, offering our support to those who need it. We are also so grateful to The Mavis Nye Foundation for this joint partnership and delighted to continue our close working relationship with Mesothelioma UK."

Leah Taylor, Mesothelioma UK Head of Nursing commented: "Mesothelioma UK is extremely grateful to the our charity partners for funding these posts. Our organisations work so well together, supporting each other and working towards the common goal of helping mesothelioma patients and their families. We're delighted that Kate, Toni and Louise will continue to be an invaluable source of information and support to patients, families, and also to her healthcare colleagues in their respective areas."

FUNDRAISING

The Power Of Your Pledge

Not everyone knows what mesothelioma is, but we do! If you believe like us, that there should be a future without mesothelioma, then leaving a gift in your will can help us to continue that fight. It's our responsibility at Mesothelioma UK to raise awareness about the dangers of asbestos exposure, collaborating with like-minded people to get the message out there whilst supporting patients and their families through their mesothelioma journey.

Putting patients first remains our key focus. Sadly, mesothelioma will be around for a long while yet and we want to help protect others. Asbestos is in the fabric of our public buildings, schools, offices, hospitals and our homes, and asbestos doesn't care how old you are or what gender you are. If you have been unknowingly exposed, you are at risk, therefore we must carry on the fight against it and you can help us to do that.

Everyone should have a will. You are never too young or too old to have a will, we never know what life will throw our way but you will have peace of mind knowing that your family will know exactly what your wishes are.

If you are unsure or struggling in any way regarding writing your will, our free downloadable guide helps you get the answers to any questions you may have. ***'What if my circumstances change?', 'How do I start?', 'How do I add a legacy to my existing will'***. These questions and more are answered simply within the guide, as well as useful contact details to give you peace of mind if you should have any further queries. www.mesothelioma.uk.com//wp-content/uploads/dlm_uploads/2021/02/LEG-03-Wills-Legacies-WEB.pdf

Gifts in wills are a vital source of income for all charities to help secure a future. They enable us to plan ahead, fund vital research into potentially life-saving treatments and maybe one day a cure. They help to fund our team of mesothelioma nurse specialists where patients and their families have access to their knowledge, support and expertise, amongst many other things.

Leaving a gift in your will is not complicated, in fact, it's quite easy, especially as members of our Legal Panel provide a professional free will writing service with all the guidance and assurance you may need. This service is available on our website at www.mesothelioma.uk.com/leave-a-gift-in-your-will/

The Power of Your Pledge Mesothelioma UK's Legacy Week takes place from 12-18 September, so there is no better time to begin thinking about leaving a gift in your will to help support Mesothelioma UK and the work it does. Your pledge will make a real difference.

Inheritance Tax can also be a worry for a lot of people but leaving a gift to a charity can help reduce the burden on your estate and help with inheritance tax. Of course, you will want to look after your family and friends first, they are your priority, but you may also want to support your chosen charity.

Mesothelioma UK's pledge to you is that we will use your donation wisely. Your donation will help us to continue our work supporting those that need it, funding research projects that specifically help patients and the specialist nurses there to support anyone affected by mesothelioma.

From the smallest to the largest, every gift matters and will make such a difference.

Most supporters leave a gift to our general funds so they can be used where they are most needed or there may be a specific area or project you would like to support, perhaps one personal and close to your heart.

Any amount, no matter the size is greatly appreciated and is a real honour. It reminds us of the continued commitment and generosity of our supporters. It's your legacy, your choice.

The power of your pledge is amazing and can change lives.

Jill Lemon, Senior Fundraiser, Legacy & Challenges Officer

Jill Lemon

Charity Ball Raises £20k

During the past 10 years, JDR Cable Systems Ltd. has raised over £146,500 for its selected charities and Mesothelioma UK has benefitted tremendously through their efforts.

The company held a charity summer ball, 'The Bright Colours Ball', on Friday 27 May 2022. The event raised over £20,000 for Mesothelioma UK and Readley and guests enjoyed a fun filled evening of raffles, games, auctions and much more.

JDR Charity Events is now looking forward to its karting event on 1 October – the proceeds of which

will, once again, be donated to Mesothelioma UK and support group, Readley.

Mesothelioma UK is very grateful to JDR Cables for its continued support and fantastic fundraising events.

Casella team runs the Bedford 5K

Members of staff from Casella UK, based in Kempston, Bedfordshire, led by Alan Mutch, Technical Product Manager, took part in the Doug Anderson 5K. The run was organised by Bedford Harriers AC in Bedford Park on Wednesday 20 July to raise funds for Mesothelioma UK.

Casella is a global leader in the manufacture and supply of occupational hygiene and environmental monitoring equipment including air sampling pumps that detect asbestos and other hazardous materials.

Despite an atrocious downpour of heavy rain throughout the whole event, all ten members of the team successfully completed the course, led home by Alan himself, in a time of 25 minutes.

Through their tremendous effort, they raised £1,100 for Mesothelioma UK through personal pledges/ sponsorship and an internal raffle.

Sarah & family take on Leeds challenges

by Sarah Gaunt

After the shock of my dad being diagnosed last June with mesothelioma, as a family we wanted to give back to the charity that has shown my dad and all of us incredible support since day one and continues to do so.

My son Reuben started off our fundraising last December by doing the 20 rugby passes per day for 20 days which led to a large amount being raised. We continued our fundraising by my husband and I taking part in the Leeds 10k on Sunday 3 July. Followed by my husband Andrew, myself, our two children Jake and Reuben and my nephews Zak and Lukas taking part in the Leeds 5k Inflatable race to finish off our fundraising and seeing us achieve over our fundraising target.

I'm sure this won't be our last fundraising event as we will continue to support this charity who has been our lifeline.

Unfortunately Ray Howard has since passed. His family has pledged to carry on his legacy by raising money for Mesothelioma UK and thank the charity for all their support.

Residents of Lon Pen y Coed fundraise on Action Meso Day

by Debra Yeates

We, the residents of Lon Pen y Coed, Swansea held a Jubilee Street Party on Friday 3 June 2022 which everyone enjoyed. We were even more pleased that we raised over £1,000 on the day. In addition, the local councillors attended the party and have also donated monies on our behalf.

Unfortunately, two of our residents (Andre and Derek) are suffering from mesothelioma and another with a different cancer (Mark).

Therefore, we have split the monies raised and made donations to Mesothelioma UK, Mavis Nye Foundation and Maggie's, Swansea. I can probably say not only myself but for many of us that we were not aware of mesothelioma before Andre and Derek were diagnosed. We therefore tried to raise awareness in the street on Action Mesothelioma Day (AMD) on 1 July 2022 by flying blue bunting from our houses and having a get together with us all wearing blue. We wore blue ribbons to raise awareness, we sold these and therefore raised more monies.

In addition, the Guildhall in Swansea lit up in blue, we shared the news on social media using the hashtag #GoBlueFor Meso.

Kirsty and family raise awareness for Mesothelioma UK

by Kirsty Mcnally

My mum was diagnosed with mesothelioma in March 2022 at the age of 62.

As a family we were devastated by the news. However, she is determined that she will fight this disease and we as a family will do everything in our power to support her. Every Thursday we meet for a family tea, my mums' grandchildren adore their nana and from day one have been asking what they can do to help nana get better. They were more than happy to have their picture taken with the flag and agreed to share it far and wide on their social media accounts to raise awareness.

Many people haven't even heard of mesothelioma including myself so it's great that since seeing the picture of the flag people have been asking about what the condition is, having this picture featured in the magazine of my mum's precious grandchildren will make her day.

Team Horner - Walking for Rusty

by Lois Roberts

In January 2020, we sadly lost my dad, Russell Horner, to peritoneal mesothelioma. On 14 May, Team Horner got together for a second time to complete the Yorkshire Three peaks challenge to raise money for Mesothelioma UK.

We had an amazing day for it, the sun shining down on us as we started the challenge from Horton in Ribblesdale. A special mention has to go out to Robin Goldring, who not only completed the challenge but completed the Leeds Half Marathon the weekend before for Mesothelioma UK.

Thanks to amazing support from friends, family, and colleagues, we raised £3,111 (inc. Gift Aid). A massive thank you to all those that took part, whether that be walkers, supporters or donators. Here's to our 2023 challenge and our future fundraising for a special charity and in memory of a wonderful man.

Muffins for Meso 2022

Our first in person Muffins for Meso took place on 19 May this year and it was our best one yet! We had 40 fabulous fundraisers and groups sign up to the campaign and raised almost £3,000! We'd like to thank everyone involved and we cannot wait to see you and your brilliant bakes next May.

The Hearns & the Yorkshire Three Peaks

Jon and Nick sadly lost their lovely dad to mesothelioma in January of this year. So on the 9 July, joined by his grandsons' Jordan and Ayden and nephew, Jonathan, they took on the mighty Yorkshire Three Peaks Challenge. Not only that, but Nick had his own challenges as in June 2021, doctors found a tumour in his spinal column which was very close to paralysing him.

After undergoing surgery in July to remove the tumour, he then started months of rehabilitation to build the strength back in his legs which has now taken him to complete Pen-y-Ghent, Whernside and then Ingleborough, a total of 24 miles and 5,200 feet of ascent, supported by his wonderful family!

This was a fantastic achievement all round and their lovely mum, sister Louise, Charles and Anna were there on hand to provide much needed support and refreshments in the form of liquids, ice lollies and of course, to give attention to their sore feet. Ayden used his grandad's rucksack, so he was there in spirit with them all.

They would like to thank all of their supporters who have helped them raise a wonderful £3,370.36 in memory of Ricky.

Volunteers

Hats off to Denise

A few months ago I started thinking about how I could raise awareness locally for 'Go Blue for Meso' on 1 July.

As a tailor, I meet many different people and am fortunate to have a loyal client base. One client, now friend, Jule Harries has embarked on a personal fundraising challenge of completing 100 open water swims wearing a different hat each time! Jule started her 'One Hundred Hats Challenge' in November last year, donning a tin hat to mark Remembrance Sunday.

Jule tries to coordinate her swims within a few days of a celebration, awareness or special day and likes to create a hat for the occasion.

At the end of May, I approached Jule to ask if she was planning a swim on or around Friday 1 July (Action Mesothelioma Day) and if she would like an idea for a hat design, which would help promote the national campaign 'Go Blue for Meso', which I was trying to promote in the Reigate and Redhill area.

Jule was more than happy to make and wear a special hat to support mesothelioma and myself. Jule was aware that I had lost my dear Dad to mesothelioma in March 2020 and she explained how her uncle was a doctor in the navy and his research specialism was on asbestosis in sailors working on ships.

So we collaborated and Jule designed and created this incredible lung hat. She spent over eight hours completing the flowers and fine details. On the morning of Tuesday 28 June, we met at The SHAC, Buckland, in Surrey and Jule swam her 62nd swim wearing the hat. It was a windy start to the day so quite a challenge swimming with the hat on her head!

I had contacted the local press who came out for the occasion and two days later we were page three girls in The Surrey Mirror!

The hat far exceeded my expectations. Jule loves hats, collecting hats and making them. The colours and design of the hat are spot on with the charity logo and certainly raises attention and a few smiles, whilst promoting a very serious cause.

I am so grateful to Jule for dedicating her time and commitment, creating an iconic hat to help raise awareness of mesothelioma and the ongoing risks of exposure to asbestos in this country.

Mesothelioma UK has since donated money to Jule's 'One Hundred Hats Challenge', in return for ownership of the hat!

The hat will be on display at the Patient and Carer day in Nottingham on 6 October. Long term, the hat will sit in reception at head office near Loughborough and perhaps sneak out for fundraising opportunities...

There is potential to create more hats with different designs for fundraisers to wear on hikes, runs, rides etc - any ideas, please contact Jill Lemon at jill.lemon@mesothelioma.uk.com

Nile's volunteer journey

Our photography volunteer Nile Ateem has been attending events since he started volunteering with us in January this year. Nile has attended the London Landmarks Half Marathon, the Cotswold Way challenge, he joined Denise Burwell at East Surrey Hospital to promote the Go Blue for Meso campaign in July, and he will be joining us at Patient & Carer Day and awards night in October.

His picture graces the front cover of this magazine. Thank you, Nile, for your continuous support!

If you are interested in volunteering for Mesothelioma UK take a look at www.mesothelioma.uk.com/volunteer-for-us/ or use the QR code opposite.

Christmas Carol Off

Join us for the 2022 Mesothelioma UK Christmas Carol Off! It's so easy to take part and there's lots of fun to be had for everyone!

Sign up, choose your song, get meeting or zooming with your friends and family to record your performance, and send us your video entry for judging.

There are three categories - Best Vocal Harmony for all those budding singers; Best Performance and Musicality for those who play an instrument(s) including spoons, kazoo, recorder, anything goes; Best Entertainment and Presence for those lacking in the singing and instrument playing department! Just dress up and perform!

The Rules

- Teams can enter of any size and any age, choose your team leader and pick a team name
- Each adult to donate £5 to take part (children under 18 are free)
- Donations to be paid by the Team Leader for all adult team members on registration (you can add more team members at any time)
- Teams can sign up on our website – choose your category and song
- Each team leader will receive a song sheet via email
- All entries to be in by midnight 7 December 2022 and will be featured on our website until 14 December 2022
- A panel of independent judges will vote for the three winning teams which will be announced at our Facebook Christmas Quiz on the 15 December 2022
- The winning entries will feature on the Mesothelioma UK website from 16 December until 31 December 2022 and each winning team will be presented with a certificate

For more information, email Jill Lemon, Senior Fundraiser at jill.lemon@mesothelioma.uk.com

Come and join the fun!

Mesothelioma UK exists to provide services for the treatment and care of mesothelioma patients across the UK. Any sponsorship, grants or donations made to the charity support this activity.

Mesothelioma UK would like to thank all of our wonderful donors. If you would like to find out more about becoming a corporate donor, please contact us on **0800 169 2409** or email **info@mesothelioma.uk.com**

Please donate to Mesothelioma UK if you can.

2022 Events

September

26 September
Webinar: Palliative Care Study with Sarah Hargreaves & Clare Gardner
www.mesothelioma.uk.com/events

October

6 October - 9am
Patient & Carer Day at Nottingham Belfry

6 October - 7pm
Third Annual Awards Night at Nottingham Belfry

27 October - 8pm
Halloween Quiz
www.facebook.com/therealmesouk

31 October
Webinar: Meso Bank Update with Robert Rintoul
www.mesothelioma.uk.com/events

November

28 November
Webinar: NCRI Mesothelioma Subgroup with Peter Szlosarek
www.mesothelioma.uk.com/events

December

7 December - midnight
Christmas Carol Off entry deadline

15 December - 8pm
Christmas Quiz Facebook Live with Simon Bolton
www.facebook/com/therealmesouk

Please visit our website for information on all our challenge events www.mesothelioma.uk.com/our-challenges/

Many thanks to our Mesothelioma UK Legal Panel supporters in England and Wales

fieldfisher
NOVUM LAW NOVUMLAW.COM
THOMPSONS SOLICITORS STANDING UP FOR YOU
Asbestos Law Partnership LLP
IM irwinmitchell
Leigh Day
Slater Gordon Lawyers
rwk goodman
HUGH JAMES
SIMPSON MILLAR

Many thanks to our Mesothelioma UK Legal Panel supporters in Scotland

DIGBY BROWN because it matters...
IM irwinmitchell