Summer Edition 2021

MESOTHELIOMA UK

MESOTHELIOMA MATTERS

Cover Feature | Page 25

New Chair of Trustees completes amazing cycling challenge fundraiser

Inside Mesothelioma Matters

Page 2 | New UK HQ taking shape

Page 15 | MESO-PRIME clinical trial launched

Page 22 | New Clinical Nurse Specialist appointed in Scotland

New UK headquarters for Mesothelioma UK

Mesothelioma UK is moving its UK headquarters into new offices on Loughborough Road, Mountsorrel, in Leicestershire. Work is currently ongoing to develop the former local authority building into new office facilities for Mesothelioma UK's Operations Team including 12 staff covering administration, finance, business development, research, events and fundraising.

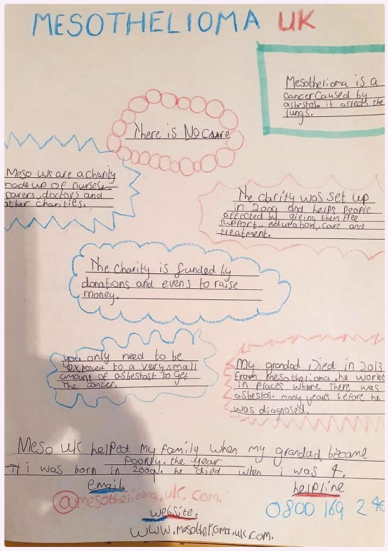
The charity will be moving out of its existing facilities in Leicester when the new offices are ready in summer 2021. The purchase of the building has been privately funded and this, along with the whole refurbishment, is being supported by Walter Miles Electrical Engineers Ltd which has a long-standing relationship with the charity.

Liz Darlison, Chief Executive Officer said: "The charity has grown from humble beginnings as a basic information service for mesothelioma patients and their families. We now manage a UK-wide network of 33 Clinical Nurse Specialists, providing amazing treatment and care to mesothelioma patients, in addition to funding a range of research projects and being a voice for patients, families, carers and other healthcare professionals on the national and international stages.

"The headquarters move is the next stage in our evolution and we simply wouldn't have been able to do this without the help from the team at Walter Miles and also the dedicated trades people who are getting the offices ready for us. We will be eternally grateful for their support so we thank them all on behalf of the entire mesothelioma community."

A perfect poster

School pupil, Grace, aged 11 from Bury, Greater Manchester was recently asked by her teacher to produce some information to tell people about a charity. Grace chose to write about Mesothelioma UK and produced this fantastic poster.



Grace knew about the charity because her grandfather had received support from us before he died when Grace was just four. Well done and thank you to Grace for raising awareness of mesothelioma and the charity at her school.

Cancer 52 patient survey

Cancer 52, an alliance of over 90 organisations, united in improving the future for everyone affected by rare and less common cancers, has published the results of its patient survey in which many mesothelioma patients took part.

This patient survey, which looked at the impact of the Covid-19 pandemic on people with rare and less common cancers, ran from early December 2020 to mid-January 2021. Over 500 people from across England responded.

Some of the key findings included:

- People diagnosed since the pandemic faced delays - either because they were concerned about contacting their GP or test and scans had been delayed
- One in 10 people who had received treatment since the pandemic began had not had the type of treatment they were expecting to receive
- One in 10 people had not been able to access their GP during the pandemic. 20% had been able to see their GP in person and 70% had been able to have a virtual or telephone appointment

The results can be seen at www.cancer52.org.uk/single-post/cancer52-publishes-england-results-of-its-second-patient-survey and are also being shared with NHS England, and other key stakeholders in the charity sector and industry.

One Cancer Voice: Plotting a route out of the pandemic

Led by Cancer Research UK, Mesothelioma UK joined 46 other cancer charities to give the UK and devolved governments a united message: we are ready to work with you to help plot a route out of the pandemic, and towards world-leading cancer services.

The cancer community is ready to work with governments across the UK to drive efforts to prevent cancers, diagnose more patients at an early stage, and get all care and clinical trials back up and running. We are urging governments and the NHS leaders across the UK to:

1. Direct resources to clear the cancer backlog as quickly as possible
2. Continue to encourage people with signs and symptoms of cancer to seek help from their GP
3. Expand the number of staff in key cancer professions
4. Drive earlier and faster diagnosis
5. Ensure personalised care and support for all
6. Strengthen the UK's medical R&D base to accelerate improvements in cancer outcomes
7. Resource high quality end of life care
8. Be bolder in measures to prevent cancer
9. Reduce inequalities in cancer outcomes

You can read the full One Cancer Voice statement at www.mesothelioma.uk.com/news/one-cancer-voice-plotting-a-route-out-of-the-pandemic

Mesothelioma CEO joins iMig Board

Mesothelioma UK CEO and Nurse Consultant at University Hospitals Leicester, Liz Darlison is honoured to have been selected to join the International Mesothelioma Interest Group (iMig) Board.

Liz is the first nurse to be appointed to the board and joins 16 other mesothelioma experts from around the world to be a part of the organisation which hosts the renowned iMig conference. iMig is an independent international group of scientists and clinicians working to understand, cure and prevent mesothelioma.

Liz Darlison said: "I have enjoyed and benefited from my iMig membership for many years. I feel honoured to join the board and will do all I can to enhance iMig's activities and reach."

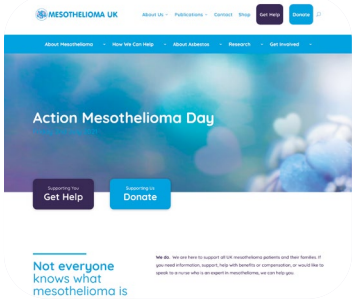
The aims of iMig are:

- To hold an international mesothelioma conference on alternate years, alternating between Europe and USA, generally as a satellite to either the respiratory or cancer research meetings on either continent
- To improve collaboration by generating a list of available resources such as cell lines, monoclonal antibodies, probes, etc. as well as making available a list of current research projects and other laboratory techniques that might facilitate collaboration
- To produce a newsletter for members on a regular basis
- To foster international interest groups to address specific issues of importance, e.g. early diagnosis, thoracoscopy, comparison of national mesothelioma registers, etc.

Our new-look website

Mesothelioma UK aims to provide as much information and advice as possible to patients and carers and our website is an important source of news and information. We want our patients to be able to access the information they need quickly and easily, so we have been working on a new website.

The new-look site at www.mesothelioma.uk.com contains all the same news, information, and resources as before but has a fresh new feel to it and is now easier to navigate.



We were grateful for feedback from a group of volunteers who tested using the site before it went live and we hope you will be able to find everything you need. Please take a look and if you have any feedback on the new site, let us know by emailing meso@sandstarcomms.com

First Clinical Expert Panel meeting

Mesothelioma UK held the inaugural meeting of the charity's Clinical Expert Panel on 17 May. This panel brings together mesothelioma experts from across the UK and from all specialities within the patient pathway. More than 25 medical professionals including chest physicians, pathology, palliative care, radiologists, surgeons, clinical nurse specialists and oncologists were there with representation from all disciplines and all four UK nations.

The online session was chaired by Professor Kevin Blyth, Queen's University Hospital Glasgow with facilitation support from Shelagh Feeney of Scarlet Oh! Consulting.

The aim of the meeting was to bring mesothelioma experts together to identify facilitators and barriers to achieving optimal patient treatment and care across the UK. The facilitator helped tease out the priorities and identify where Mesothelioma UK could perhaps have the greatest impact.

A pre-meeting survey set the scene; panel members were split into four groups who each brainstormed on a different issue and presented back to the main panel.

There was a plethora of ideas for Mesothelioma UK to consider with much discussion around the need for clinical champions in hospitals and across cancer alliances/regions.

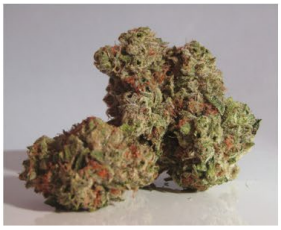
It was a vibrant and industrious meeting and there is no doubt the overall message from the meeting was one of hope, with chair Prof Blyth, in his closing, saying he was "hopeful that we can overcome the barriers faced by patients". He also added that patient power can't be underestimated as a tool for driving change within the NHS.

Mesothelioma CEO Liz Darlison and Chair of the Board Dr Nick Maskell, who both attended the meeting, will now use the consensus of the panel to identify the areas the charity can support going forward that will have the biggest impact on patients and their families. The charity's public advisory board and nursing team will review the Clinical Expert Panel findings before the board of trustees approve the content to be included in Mesothelioma UK's Strategy 2021-2024.

Going forward, the Clinical Expert Panel will support the charity as required with content, reviewing documents and offering an opinion in between the annual meeting.

Mesothelioma UK would like to thank Shelagh Feeney from Scarlet Oh! Consulting for her expert facilitation, Prof Blyth for chairing and each panel member for giving up their time and for their enthusiasm throughout.

Cannabis medicine



Mesothelioma UK has been asked on a number of occasions about the benefits of cannabis medicine for people living with mesothelioma. Whilst there is no evidence exploring their use specifically in mesothelioma, we thought that we would reach out to Patrick Kendall from Grow Pharma to explain a little more...

Since November 2018, private specialist consultant doctors in the UK have been able to legally prescribe cannabis-based medicine products (CBMPs) to patients they feel will benefit from these treatments. Public awareness and knowledge of these medicines, their applications in terms of what symptoms they can help to manage and general understanding about their availability is still low.

There is a constant flow of new research into the uses and application of cannabis medicines. The evidence to support their benefits in different indications provides important guidance to doctors. Cannabis medicines do not cure, but they can help to manage symptoms of a broad range of conditions. This includes chronic and neuropathic pain, cancer pain, spasticity in multiple sclerosis, unmanaged epilepsy and chemotherapy-induced nausea and vomiting.

Within the remit of their specialism, all private doctors can prescribe medical cannabis if they feel that the patient will benefit from it. Not every doctor has been trained or is aware of this. At the same time across the UK, specialised clinics have opened where doctors have been specifically trained in cannabis medicines. These clinics are available for anybody to access privately.

The two main constituents of many cannabis medicines are cannabidiol (CBD) and tetrahydrocannabidol (THC). The two provide different benefits and often provide the most benefit together. Cannabis medicines come in a wide range of formulations and various ratios of THC and CBD: flower taken via vaporisers, THC and/or CBD-containing oils and sprays or capsules. The dosing and balance of THC and CBD in any formulation is tailored to the patient's clinical need and therapeutic requirement.

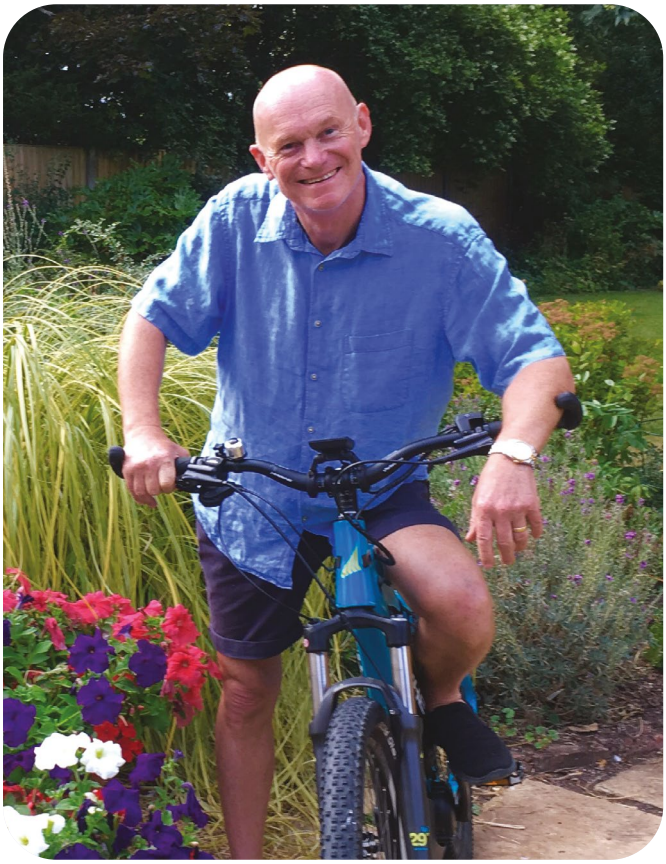
To learn more about cannabis medicines, their application, and the practicalities of accessing them, speak to your mesothelioma clinical nurse specialist, GP or consultant, or you can visit a number of websites including:
www.nhs.uk/conditions/medical-cannabis

www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/complementary-alternative-therapies/individual-therapies/cannabis

www.opencannabis.uk

Please note: the publication of this article should not be taken as an official endorsement or recommendation by Mesothelioma UK. Mesothelioma UK undertakes no responsibility for the accuracy of any information contained in non-related websites or given by non-related organisations.

A patient's perspective on taking cannabis for medical reasons



After extensive research, mesothelioma patient, Tim Stokes from the Midlands took the decision to use cannabis to help him cope with some of his own symptoms including anxiety, nausea, insomnia, and loss of appetite.

Tim explains: "After my diagnosis, I began to research the medicinal benefits of cannabis and also spoke to oncologists about its effects, so I felt fully informed before taking it. In particular, I understood that the THC and CBD compounds contained within cannabis could help me.

"I've tried taking it as an oil, orally and smoking it, but have found that vaping is the most effective form of ingestion for me, personally. There are many different strains and I've managed to identify a strain that delivers what I need.

"I only take it at night to help me sleep now, as it has a soporific effect on me. It stops me feeling so anxious about the disease and enhances my pleasure emotions so I've found myself better appreciating food, art and music, for example. It also acts as a mild painkiller so reduces aches but not acute pains.

"I've been open with all of the medical professionals that I've seen as a patient about how and why I take it. It's still safer than alcohol but does also have its downsides – it can lead to short-term memory loss, it can affect my judgement so I don't drive, and the compounds are present in your body for up to three days after you've taken it so you wouldn't pass a random drugs test!

"It's been over six years now since my diagnosis and I'm in my mid-60s. Although I plan to continue to take cannabis, I've stopped all treatment and am on palliative care only."

You can read more about Tim's patient story at www.mesothelioma.uk.com/patientstories/tim-stokes/

Please note: the publication of this article should not be taken as an official endorsement or recommendation by Mesothelioma UK. Mesothelioma UK undertakes no responsibility for the accuracy of any information contained in non-related websites or given by non-related organisations.

Introduction to Sarah Cannon Research Institute

Sarah Cannon Research Institute, part of HCA Healthcare UK, is an early phase oncology drug development unit that was established in 2010 and enrolled its first patient in 2011. Sarah Cannon Research Institute-UK sees patients from the NHS and the private sector, and currently has more than 45 active clinical trials and over 200 patient visits per month.

Within its centre on Harley Street, there are two clinics, a pharmacy, a laboratory, and a dedicated team of doctors, nurses, pharmacists and support staff. Alongside this is the Sarah Cannon Molecular Profiling Group to access genetic profiling – a service that has been used by more than 2,000 patients thus far.

Its clinical trials are free, and travel costs and accommodation are reimbursed as well. With patients being referred to the centre from all over the United Kingdom, this can be helpful when coming to visit Sarah Cannon Research Institute-UK.

It encourages oncologist, general practitioners and specialist nurses to send referrals for their patients during the early stages of diagnosis when it can explore future treatment options and, with permission, keep details within records should a new trial become available.

Sarah Cannon Research Institute-UK has a friendly, experienced and approachable team who put people who live with cancer at the heart of every decision they make.

Through clinical excellence and cutting-edge research, Sarah Cannon is redefining cancer care around the world.

It currently has molecular screening and trial options for patients with mesothelioma. If you would like to be considered for one of their clinical trials, please ask your oncologist to send a referral letter to: referrals.scri@hcahealthcare.co.uk

Support UKNAR's '1,000 Schools In 2021' Multi Academy Trust Asbestos SMART Campaign

UKNAR (UK National Asbestos Register) CIC is proactively targeting estates teams and senior decision makers at Multi Academy Trust schools across the country to sign up to live asbestos awareness presentations this summer, as part of its '1,000 Schools in 2021' campaign.

The 20-minute presentations will explain how today's simple technology can be used to enhance existing contractor asbestos management procedures in schools and how to better protect staff and pupils by reducing the risk of accidental asbestos disturbances and exposures.

Andrew Paten, Co-founder, UKNAR comments: "We are hoping 1,000 schools will adopt Asbestos SMART this year, for as little as £200-300 per school. This is still only about 5% of UK schools that contain asbestos, but it will better protect hundreds of thousands of pupils, staff and contractors. We aim to make a huge difference in increasing levels of asbestos awareness in UK schools, where so many people remain vulnerable. We are making a call to our asbestos community to get behind the campaign by referring schools and education business leaders to us so we can have the important conversations, share information and save lives."

If you know a school, college, university, employer, dutyholder or workplace that could benefit from Asbestos SMART, please introduce UKNAR. 5% of Asbestos SMART's licence fees go to Mesothelioma UK as UKNAR's charity partner.

To refer a Multi Academy Trust or a local school in your area, please contact: stuart.towers@uknar.org

Carers' Hour

In April, Mesothelioma UK held its first 'Carers' Hour'. The online meeting was for carers of mesothelioma patients to come together, hear from experts and share their experiences with other carers.

Members of the Mesothelioma UK team including a panel of our Specialist Nurses were in the meeting to answer any questions. In addition, guest speaker Janet Parkinson, Macmillan Support and Information Manager spoke to the guests about the importance of carers taking time to take care of themselves.

The meeting proved very useful for carers so a monthly Carers' Hour will now take place to give carers a safe environment in which to put questions to our Clinical Nurse Specialists and share experiences.

If you are a carer for a mesothelioma patient and have any questions for our nurses, we would love you to join us for our Carer's Hour meeting. Check www.mesothelioma.uk.com for details of future events.

Mesothelioma Matters webinars

Since November, we have hosted monthly Mesothelioma Matters webinars. These virtual meetings feature guest speakers including researchers studying cutting edge treatments, thoracic surgeons, lung cancer consultants, oncologists, and clinical nurse specialists.

The webinars take place online and are free for anyone to join live or watch at a later date. An average of 152 people have attended the webinars so far with almost 700 watching them on YouTube. Feedback is very positive with people finding them useful and informative.

Webinars for the rest of the year are:
24 June – Armed Forces Day
28 June – Research Prioritisation
26 July – Living Well with Mesothelioma
6 September – Combination Immunotherapy in Mesothelioma
27 September – Mesothelioma PhD Showcase

If you can't join us live for any of the webinars, they are uploaded to our website and YouTube channels so you can watch them in your own time.

In conversation with…

Many of you will have seen some of our 'In conversation with…' interviews which we've been doing since April 2020.

We wanted to stay connected with the mesothelioma community and wanted our patients, carers and supporters to remain informed during the pandemic when they may not have been able to see their clinical nurse specialist in person.

Our CEO, Head of Nursing and Team Leaders have all conducted interviews with a range of people including clinical experts, patients, carers, support groups, researchers, advocates, nurses, and other professionals in the field of mesothelioma and asbestos.

Ivan Cartwright, Area Coroner for Leicester City & South Leicestershire

The videos of the interviews are all available on our Facebook page and YouTube channel so you can watch them any time. So far, over 24,700 people have watched the interviews which is fantastic as we know we are reaching many people and raising even more awareness of mesothelioma. The patient interviews in particular have been watched by thousands of people, showing the importance of sharing experiences and the comfort of hearing from others in a similar situation.

Please visit our Facebook page (@therealmesouk) or our YouTube channel ('Mesothelioma UK') to watch any of the interviews.

Action Mesothelioma Day 2021 – book your place!

Registrations are now open for the Action Mesothelioma Day 2021 national virtual event.

Mesothelioma UK will be collaborating with the UK Mesothelioma Alliance (UKMA) and ActionMeso.org to celebrate #ActionMeso Day 2021 and encourages everyone to join us and celebrate this special day. This event will be hosted by broadcaster, academic and peritoneal mesothelioma patient, Kate Williams.

Action Mesothelioma Day (shortened to Action Meso Day) will be held on Friday 2 July 2021. This will be a virtual event aimed at raising awareness about mesothelioma and inviting everyone to take action to eradicate this disease.

This year, ActionMeso will host a national virtual event including panel discussions, clinical trials updates and interesting facts and insights for anyone new to mesothelioma. Mesothelioma UK CEO Liz Darlison and Head of Nursing Lorraine Creech will be live on our Facebook page from 12:15pm before introducing the main event, and back again from 1:35pm with a Q&A.

ActionMeso is a collaboration between the key asbestos charities and support groups dedicated to raising awareness amongst the general UK public and calling upon companies and the government to take action.

Find out more and register for a ticket by visiting www.actionmeso.org

Mesothelioma UK at iMig 2021

The International Mesothelioma Interest Group (iMig) is an independent international group of scientists and clinicians working to understand, cure and prevent mesothelioma. The iMig annual, multidisciplinary meeting was held virtually this year and brought together delegates from around the world. It featured the most up-to-date research, diverse topics of interest, and educational sessions with leading experts.

Among those experts were members of the Mesothelioma UK nursing team. The charity was represented 37 times at the event and involved in 23 presentations. This included seven Mesothelioma UK clinical nurse specialists presenting their work, two nurses chairing sessions, two presentations on Mesothelioma UK-funded research and seven presentations by the Mesothelioma UK Research Centre at Sheffield. In addition, the charity was involved in 14 poster presentations.

Presentations included:

- A Mesothelioma Case Study – a Global Perspective
- Evaluation of Mesothelioma in a Large District Hospital
- Non-NHS Funded Therapy v Clinical Trials
- The Impact of COVID-19 on the Experiences of People with Mesothelioma
- Patient Experiences in the MARS2 Study
- The Role of the Clinical Nurse Specialist in the Patient Journey

Liz Darlison, Mesothelioma UK CEO commented: "To be able to share our research at this eminent conference will really help to raise awareness of the work of the charity and our partners on an international level. We're proud to be building a reputation as internationally-renowned experts in mesothelioma and the patient experience."

Latest 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 to UHL clinical librarians!

New scientific research

Recurrence of mesothelioma after a macroscopic complete resection procedure: is a second radical surgery justified?
Author(s): Elsayed, Hany Hasan; Hassaballa, Aly Sherif; Ahmed, Taha Aly; Sharkawy, Hazem Youssef
Source: Interactive cardiovascular and thoracic surgery; May 2021; vol. 32 (no. 5); p. 761-763
Available at Interactive cardiovascular and thoracic surgery - from Oxford Journals - Open Access

Does the LENT score risk-stratify patients with malignant pleural mesothelioma? An observational study.
Author(s): Chollet, Bertrand; Guinde, Julien; Laroumagne, Sophie; Dutau, Hervé; Astoul, Philippe
Source: Thoracic cancer; May 2021
Available at Thoracic Cancer - from Europe PubMed Central - Open Access

CAR T-cell therapy for pleural mesothelioma: Rationale, preclinical development, and clinical trials.
Author(s): Chintala, Navin K; Restle, David; Quach, Hue; Saini, Jasmeen; Bellis, Rebecca; Offin, Michael; Beattie, Jason; Adusumilli, Prasad S
Source: Lung cancer (Amsterdam, Netherlands); May 2021

SEOM clinical guidelines for the treatment of malignant pleural mesothelioma (2020).
Author(s): Nadal, E; Bosch-Barrera, J; Cedrés, S; Coves, J; García-Campelo, R; Guirado, M; López-Castro, R; Ortega, A L; Vicente, D; de Castro-Carpeño, J
Source: Clinical & translational oncology : official publication of the Federation of Spanish Oncology Societies and of the National Cancer Institute of Mexico; May 2021; vol. 23 (no. 5); p. 980-987
Available at Clinical & translational oncology: official publication of the Federation of Spanish Oncology Societies and of the National Cancer Institute of Mexico - from Unpaywall

Medical Thoracoscopy, Computed Tomography-guided Biopsy, and Ultrasound-guided Biopsy for Malignant Pleural Mesothelioma: A Systematic Review.
Author(s): Shiroshita, Akihiro; Kurosaki, Motohiro; Takeshita, Masafumi; Kataoka, Yuki
Source: Anticancer research; May 2021; vol. 41 (no. 5); p. 2217-2225

Emerging biological therapies for the treatment of malignant pleural mesothelioma.
Author(s): Davis, Alexander P; Kao, Steven C; Clarke, Stephen J; Boyer, Michael; Pavlakis, Nick
Source: Expert opinion on emerging drugs; May 2021

Extrapleural Pneumonectomy versus Pleurectomy/ Decortication for Malignant Pleural Mesothelioma.
Author(s): Zhou, Nicolas; Rice, David C; Tsao, Anne S; Lee, Percy P; Haymaker, Cara L; Corsini, Erin M; Antonoff, Mara B; Hofstetter, Wayne L; Rajaram, Ravi; Roth, Jack A; Swisher, Stephen G; Vaporciyan, Ara A; Walsh, Garrett L; Mehran, Reza J; Sepesi, Boris
Source: The Annals of thoracic surgery; May 2021

UHL Clinical Librarian Service
"bringing you the evidence"

Emerging avenues in immunotherapy for the management of malignant pleural mesothelioma.
Author(s): Gray, Steven G
Source: BMC pulmonary medicine; May 2021; vol. 21 (no. 1); p. 148
Available at BMC Pulmonary Medicine - from BioMed Central

Incidence of mesothelioma and asbestosis by occupation in a diverse workforce.
Author(s): DeBono, Nathan L; Warden, Hunter; Logar-Henderson, Chloë; Shakik, Sharara; Dakouo, Mamadou; MacLeod, Jill; Demers, Paul A
Source: American journal of industrial medicine; Apr 2021

Prognostic factors for progression-free and overall survival in malignant pleural mesothelioma.
Author(s): Guzmán-Casta, Jordi; Carrasco-CaraChards, Sonia; Guzmán-Huesca, Jorge; Sánchez-Ríos, Carla Paola; Riera-Sala, Rodrigo; Martínez-Herrera, José Fabián; Peña-Mirabal, Erika Sagrario; Bonilla-Molina, Diana; Alatorre-Alexander, Jorge Arturo; Martínez-Barrera, Luis Manuel; Rodríguez-Cid, Jerónimo Rafael
Source: Thoracic cancer; Apr 2021; vol. 12 (no. 7); p. 1014-1022

Efficacy and safety of pembrolizumab in patients with advanced mesothelioma in the open-label, single-arm, phase 2 KEYNOTE-158 study.
Author(s): Yap, Timothy A; Nakagawa, Kazuhiko; Fujimoto, Nobukazu; Kuribayashi, Kozo; Guren, Tormod Kyrre; Calabrò, Luana; Shapira-Frommer, Ronnie; Gao, Bo; Kao, Steven; Matos, Ignacio; Planchard, David; Chatterjee, Arkendu; Jin, Fan; Norwood, Kevin; Kindler, Hedy L
Source: The Lancet. Respiratory medicine; Apr 2021

Clinical prognostic factors in pleural mesothelioma: best supportive care and anti-tumor treatments in a real-life setting.
Author(s): Ringgaard Petersen, Thomas; Panou, Vasiliki; Meristoudis, Christos; Weinreich, Ulla Møller; Røe, Oluf Dimitri
Source: Acta oncologica (Stockholm, Sweden); Apr 2021; vol. 60 (no. 4); p. 521-527

Qualitative studies and patient experience

Gender and the experiences of living with mesothelioma: A thematic analysis.
Author(s): Ejegi-Memeh, Stephanie; Robertson, Steve; Taylor, Bethany; Darlison, Liz; Tod, Angela
Source: European journal of oncology nursing : the official journal of European Oncology Nursing Society; Apr 2021; vol. 52 ; p. 101966

Quality of life and lung function after pleurectomy/decortication for malignant pleural mesothelioma.
Author(s): Nakamichi, Toru; Hashimoto, Masaki; Nakamura, Akifumi; Kuroda, Ayumi; Tanaka, Takashi; Takeuchi, Jiro; Matsumoto, Seiji; Morimoto, Takeshi; Kondo, Nobuyuki; Domen, Kazuhisa; Hasegawa, Seiki
Source: Interactive cardiovascular and thoracic surgery; May 2021
Available at Interactive CardioVascular and Thoracic Surgery - from Oxford Journals - Open Access

Understanding the palliative care needs and experiences of people with mesothelioma and their family carers: An integrative systematic review.
Author(s): Harrison, Madeleine; Gardiner, Clare; Taylor, Bethany; Ejegi-Memeh, Stephanie; Darlison, Liz
Source: Palliative medicine; Apr 2021 ; p. 2692163211007379

Symptom Burden and Unmet Needs in Malignant Pleural Mesothelioma: Exploratory Analyses From the RESPECT-Meso Study.
Author(s): Hoon, Siao Nge; Lawrie, Iain; Qi, Cathy; Rahman, Najib; Maskell, Nick; Forbes, Karen; Gerry, Stephen; Monterosso, Leanne; Chauhan, Anoop; Brims, Fraser J H
Source: Journal of palliative care; Apr 2021; vol. 36 (no. 2); p. 113-120

Effects of the COVID-19 pandemic on people with mesothelioma and their carers.
Author(s) Taylor, Bethany; Tod, Angela; Gardiner, Clare; Creech, Lorraine; Forde, Faye et al.
Source Cancer Nursing Practice; Mar 2021

Mesothelioma: exploring gender differences in time to diagnosis, seeking legal advice and occupational risk.
Author(s) Senek ; Robertson, Steven; Tod, Angela; Squibb, Molly
Source Cancer Nursing Practice; Mar 2021; vol. 20 (no. 2); p. 21-27

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

CLINICAL TRIALS

New trial – MESO-PRIME

The Royal Marsden NHS Foundation Trust sponsored study, MESO-PRIME: Pembrolizumab and Hypofractionated Stereotactic Radiotherapy in patients with Malignant Pleural Mesothelioma, opened to recruitment in January 2021 and has now recruited three patients across its two participating centres.

This study is looking at the safety and effects of using SBRT with pembrolizumab given at the same time. Pembrolizumab is a potent and highly selective humanized monoclonal antibody (mAb) of the IgG4/kappa isotype designed to directly block the interaction between PD-1 and its ligands, PD-L1 and PD-L2.

The primary objective of the study is to assess the safety and tolerability of 30 Gy in three fractions over a week delivered via SBRT in MPM in combination with pembrolizumab. The secondary objectives include describing the safety profile of SBRT in MPM in combination with Pembrolizumab, assessing the clinical benefit by calculating the overall response rates and disease control rates as well as progression free survival and overall survival, assessing responses rates in epithelioid versus sarcomatoid histological subtypes of MPM and assessment of response rates in relation to tumour PD-1/PD-L1 expression.

This is a phase I, single arm, open label study for patients with advanced malignant pleural mesothelioma. This study will recruit up to 18 patients whose MPM has progressed beyond first-line of palliative chemotherapy, with a platinum-based doublet, and now requires further palliative systemic treatment, or have declined first-line palliative chemotherapy, however must have been considered suitable for a platinum doublet chemotherapy.

The study will be conducted in two parts; an initial safety phase (Part A), followed by an expansion cohort (Part B). The initial safety phase (Part A) is based on a 3+3 design such that patients will be treated in a cohort of three to six patients. A maximum of six patients will be allocated to Part A exploring SBRT 30 Gy in three fractions in combination with pembrolizumab.

If there is more than one DLT in the first three patients or two or more DLTs in the first six patients, this treatment combination will be deemed as being unacceptable and it would lead to termination of the study. During the expansion cohort (Part B), 12 patients will have SBRT 30 Gy in 3 fractions with pembrolizumab to obtain additional safety and response data. Maintenance pembrolizumab will continue until disease progression, unacceptable toxicities, the patient withdraws consent to the trial, or the patient has completed 35 cycles of treatment.

Further information regarding the study can be found on clinicaltrials.gov (NCT04166734) or by contacting the study team on mesoprime.trial@rmh.nhs.uk

RESEARCH

Patient and carer participants required for new study

Mesothelioma UK and Lung Cancer Nursing UK recently awarded a research grant to Dr Matthew Johnson, Macmillan Lead Cancer Nurse at the Royal Brompton and Harefield Hospitals.

His study is looking for participants to share their experiences of a long-term (more than three years) diagnosis of pleural mesothelioma – patients and their main carer.

The researchers will be investigating the experience of people and their main carer who have been living with mesothelioma for three years or more. Existing studies have focused on people who have been diagnosed recently with mesothelioma, but there have been no studies that explore the experience of those who live with the diagnosis over a longer period.

It is hoped that the study can help improve the care and support offered to people affected by mesothelioma and give valuable insight into the experiences of those whose survival proves much better than expected. So far there has been a lot of interest and several patients and carers have been interviewed – but more are needed.

Taking part will involve being interviewed via video call or telephone call. There is also a focus group planned later in the year. Interviews can either be with both the person diagnosed with mesothelioma and the carer together, or if you prefer, these can be arranged separately. If you do not have someone you identify as your main carer, you can still join the study on your own. Interviews will be undertaken by an experienced qualitative researcher and are expected to last about 60 minutes.

Participants should be:

- diagnosed with pleural mesothelioma three or more years prior entering the study or
- a significant informal carer (wife, husband, daughter, son, or close friend) to the person diagnosed with pleural mesothelioma
- aged over 18 years
- able to verbally communicate fluently in English
- able to give informed consent to participation

If you meet the criteria and would like to find out more about taking part in this study, please call the Mesothelioma UK information line on 0800 169 2409 or email info@mesothelioma.uk.com

Mesothelioma Patient and Carer Experience Research Prioritisation Exercise Invitation

This is an invitation to take part in the Mesothelioma UK Research Centre's mesothelioma patient and carer experience Research Prioritisation Exercise survey.

The purpose of this exercise is to identify unanswered questions about the mesothelioma patient and carer experience in the UK and to prioritise these areas, through consultation with patients, carers, and professionals.

This exercise is being undertaken by the Mesothelioma UK Research Centre team at the University of Sheffield.

The survey will involve answering some brief questions about yourself. Following this, you will be asked to watch eight short video recordings, each 1-2 minutes long, that present identified research gaps. The survey will then ask how important you consider these research gaps and about any additional topics or aspects of the patient and carer experience that you consider to be in need of further research. The survey is open until Sunday 27 June 2021.

The link to the survey can be found on the website at www.sheffield.ac.uk/murc/our-research. The research team is grateful to all participants as they will be contributing to research to improve the experiences of people living with a mesothelioma diagnosis.

If you have any questions or concerns, please do not hesitate to contact the team at mesotheliomaresearchcentre@sheffield.ac.uk

If you would like to join the Mesothelioma UK Research Centre mailing list, and get an update about this and other projects, you can sign up on the website at www.sheffield.ac.uk/murc/our-research

LEGAL PANEL

HSE Report 2020: The Changing Face of the UK's Asbestos Legacy.

By Sarah Wolf, Partner in Royds Withy King's Industrial Disease Team and head of Asbestos Disease in the company's London office

The recently published report from the Health and Safety Executive provides a statistical analysis of deaths from mesothelioma between 1968 and 2018.

I suspect that many of us are weary of statistics at a time when we are bombarded with daily COVID updates, and we can never forget that each statistic represents a life tragically cut short and a terrible loss for a family and community. However, it is in large part due to statistical research that knowledge of the risks associated with asbestos exposure has grown since the early 1900s. This has led to the introduction of safety measures and regulations designed to protect and compensate those exposed, and to the development of medical treatments.

Of course, mesothelioma is not the only lung disease associated with asbestos exposure, so the overall impact of this country's asbestos legacy is far greater than a study of mesothelioma cases alone would suggest. However, as mesothelioma has such a strong association with asbestos exposure, this report provides a focused analysis of trends relating to the age, gender and occupation of those affected by this terrible disease.

The fact that there tends to be such a long period between exposure and manifestation of symptoms means that most people diagnosed with mesothelioma today were most likely exposed during the period 1950 – 1980, when there was widespread industrial use of asbestos in this country. Academic studies suggest that the UK's uniquely high mesothelioma rate is linked to the fact that we were the largest importer of brown asbestos (amosite), which was used extensively as a fire retardant.

According to the report, since the late 1960s there has been an upward trend in annual deaths from mesothelioma, although between 2012 and 2018 the figures remained broadly similar. Rates remain highest in men over the age of 70, which reflects both the latency period and the greater likelihood that they would have been exposed to asbestos at work. The ongoing decline in death rates in the under 65s reflects the impact of the controls introduced from the 1970s onwards.

A regional analysis unsurprisingly reveals that those areas of the UK with the highest mortality rates tend to be those with a significant industrial history, particularly in shipbuilding and the manufacture of asbestos products.

The study also looks at occupation and concludes that those working in the construction industry such as plumbers, carpenters and electricians, as well as pipefitters, shipbuilders, floorers and tilers were particularly at risk.

Occupational analysis of women is harder to interpret because relatively few instances can be clearly linked to occupational exposure. The suggestion is that where exposure occurred in the workplace it was more likely to have been from disturbance from work going on in the vicinity, rather than direct handling of asbestos. There is also the well-documented risk of living with someone who worked with asbestos. However, the suggestion is that the increase in incidence in both women and men who have not been exposed to an obvious occupational risk is down to the widespread use of asbestos as a building material in the 50s, 60s and 70s.

Royds Withy King was pleased to have helped to fund research into how women's experience of mesothelioma, in terms of awareness of the disease itself as well as diagnosis, access to treatment and dealing with compensation and legal claims, might differ from that of men. This resulted in the Gendered Experience of Mesothelioma Study report, available at www.mesothelioma.uk.coms/GEMS

As a lawyer who has specialised in asbestos related disease claims for many years, and has witnessed developments in this area since the early 90s, I am reminded on a daily basis not only that my clients and their families are not mere statistics, but also that the figures show only part of the picture. It is important not to make any assumptions or dismiss any potential claim that may be 'atypical', and to follow up every line of enquiry. I am dealing increasingly with cases where the source of exposure is not immediately obvious, acting on behalf of teachers, office workers and medical staff. It is also particularly shocking, for example, that those employed in the lucrative asbestos-management industry, tasked with its safe removal, are often themselves inadequately protected because of shoddy equipment and poor systems. While the overall picture suggests that cases of mesothelioma are likely to start to decline, sadly, the eradication of this avoidable condition seems remote indeed.

I would encourage anyone diagnosed with mesothelioma, even those who cannot immediately recall any specific instances of asbestos exposure, to talk things through with a specialist solicitor.

Gender issues in mesothelioma

By Louisa Saville, Associate Solicitor at Leigh Day

Historically mesothelioma has been a male dominated disease. In recent years, the number of compensation claims being pursued by women are increasing. Are more women coming into contact with asbestos? What are the real reasons behind this increase? Once diagnosed, what challenges do women have to overcome to secure compensation?

The overall incidence of mesothelioma has increased in the UK by 61% since the early 1990s. Looking at the individual genders, the increase is more pronounced. There has been a 51% increase in men, compared to a 97% increase in women. The number of cases in women is predicted to continue to increase until 2027, compared to cases in men which are predicted to decline after 2021.

How can the doubling in the number of women affected by mesothelioma be explained? Undoubtedly advances in medical science have led to better diagnosis in recent years.

Linked to this is the fact that the UK has an ageing population. People are living longer and so developing asbestos-related diseases where in the past they would not have. There is a school of thought that attributes the increase in female victims of mesothelioma to 'spontaneous' mesothelioma. That is, not caused by asbestos. There is little evidence to support this. What seems more likely is that the these 'unexplained' cases are due to low level asbestos exposure.

Over the last few years there has been a rise in awareness of the risks of asbestos in female dominated sectors such as healthcare settings and schools where more women are employed. High profile cases such as Dr Kate Richmond, a young mother who developed mesothelioma after exposure in Walsgrave Hospital as a junior doctor, have led to an increase in knowledge of the ways women may come into contact with asbestos at work.

There is no doubt that women are less likely to have stereotypical occupational asbestos exposure. For a woman, asbestos exposure at work is more likely to be due to the working environment rather than direct handling of asbestos. For example, dust released from the renovation of asbestos ceiling tiles or coming into contact with asbestos lagged pipes in basements and subterranean tunnels.

Women are more likely to have a lack of understanding and knowledge of how they were exposed and this puts them at a disadvantage from the start as it is difficult to get the evidence needed to prove their exposure when pursuing a compensation claim. If they didn't know asbestos was there, they are not in a position to identify the source of exposure. This often leads to their case being recorded as 'environmental', rather than occupational exposure.

Outside of occupational exposure, many women develop mesothelioma due to secondary exposure, where they come into contact with asbestos from another source, such as washing the overalls of a spouse or son with asbestos dust on. These cases are difficult for a number of reasons. It can be hard to corroborate secondary exposure with evidence as there may not be anyone else other than the Claimant who can give an account of what happened.

This type of exposure falls outside of the employer/employee relationship/duty and so a Claimant does not have the protection of statutory duties which benefit workers, again making it difficult to prove breach of duty. The dates of exposure are more critical; cases are only likely to succeed for exposure after 1965 due to the Court's decision in the case of Maguire. As a result of this many claims cannot be pursued.

A recent research study, The Gendered Experience of Mesothelioma Study (GEMS) undertaken by researchers at the University of Sheffield with Mesothelioma UK and other partners, found that women diagnosed with mesothelioma are less likely to pursue a compensation claim. There are a whole host of reasons for this. It often takes longer for a woman to be diagnosed with mesothelioma than a man. Once a diagnosis is reached there can be uncertainty as to the source of any asbestos exposure.

Men were found to feel a greater sense of responsibility to ensure financial security for their family. Depending on their occupation, they may know of others who had successfully pursued a claim, this is less likely to be the case for a female patient. Women generally felt that bringing a claim was a burden on the family, that it was too costly and time consuming. Practically, this delay can lead to claims being more difficult to pursue.

By the time a woman instructs a solicitor they are often very unwell, the illness has already taken hold. A solicitor may not become involved until after death at which stage the opportunity to get first-hand evidence of the asbestos exposure has been missed.

Due to the difficulties often faced by women when bringing claims – uncertainly about exposure and/or exposure at low levels – a defendant is more likely to contest the claim. This impacts on the Claimant's ability to access private medical treatment, such as immunotherapy.

Often the cost of this treatment is prohibitive and beyond the means of Claimants unless judgement has been entered in their claim and a ruling made for the defendants to cover the cost. Mesothelioma is an aggressive condition. By the time a contested claim is at a point where defendants are ordered to pay for private treatment, the Claimant may no longer be fit enough to have it.

What does the future hold for the increasing number of women being diagnosed with mesothelioma? Alongside charities like Mesothelioma UK, we continue to raise awareness of the risks faced by women in certain types of jobs and the consequences of even low levels of asbestos exposure.

Asbestos disease claims are complex, but specialist solicitors experienced in pursuing these claims are likely to have experience in winning claims for female victims of mesothelioma. By using specialist experts and the dedicated 'fast track' asbestos disease court system, these cases can be settled quickly and effectively, giving Claimants financial security and peace of mind.

APPOINTMENTS

Focus on pleural nurses

If you have received support from any of our clinical nurse specialists (CNSs), then you will know what a difference they can make. Here's a bit more about them and why they are so important on the patient journey.

Pleural clinical nurse specialists, like the Mesothelioma UK nurses, have expert knowledge in pleural diseases, including mesothelioma and malignant pleural effusions. They provide a specialist service, which is not reliant on but supports trainee doctors in looking after patients with pleural disease.

Pleural CNSs have received dedicated training in performing specialist skills such as carrying out thoracic ultrasounds and undertaking diagnostic tests and procedures to improve the symptoms of malignant pleural effusions. Pleural CNSs also have skills in symptom management, non-medical prescribing, clinical diagnostic and assessment skills which all help to improve and guide the patient's pathway.

Organisational skills are vital for pleural nurses as they plan and organise patient care to help reduce anxiety and provide support to patients, carers and their families during what can be a very stressful time.

Pleural CNSs provide continuity of care by undertaking tests, attending clinic with patients and being available on the phone. They help to build supportive relationships and act as a point of call for any questions and concerns. Having a pleural CNS on the care team allows for expectations to be managed, improved understanding of the diagnostic journey and management of symptoms.

The pleural CNS allows the patient to explore the most up-to-date research and improves access to current trials in pleural disease. Working as the patient's advocate as part of the multidisciplinary team ensures the patient's voice and wishes are heard and considered. The pleural CNS can link patients with specialised pleural services for diagnostic testing and to ensure symptoms are managed to improve breathlessness, chest pain and quality of life.

Pleural CNSs are also a specialist resource for healthcare professionals including nurses and doctors working in hospitals and in the community. The pleural CNS can provide training and education to nurses, doctors and other healthcare professionals working with patients with pleural diseases. This provides patients with more specialist care and improves the understanding of care management including chest drain care and indwelling pleural catheters.

The role of the pleural CNS will continue to develop and the role they play in a multidisciplinary team is vital for both patients and other healthcare professionals.

Four new nurses join the team

Our team of Mesothelioma UK clinical nurse specialists (CNS) is growing and we're now at 33 around the UK. Most recently we've appointed nurses in Scotland, Wales, and the Humber, Coast and Vale Cancer Alliance region.

For the Humber, Coast and Vale region, Carole Scott and Ian Collins have been appointed. Carole is based at the Northern Lincolnshire and Goole NHS Foundation Trust and Ian at the Hull University Teaching Hospitals NHS Trust.

For Scotland, Lynne Hunter has been appointed as for the South East region and will be based at the Western General Hospital, part of NHS Lothian (see more on page 22 about Lynne) .

In Wales, Sam Williams has been adopted as a specialist nurse and will work with Mesothelioma UK CNS Sarah Morgan at the Aneurin Bevan Trust.

We're well on our way to reaching our goal of 38 CNSs around the UK and we'd like to thank our supporters whose fundraising efforts help to make this possible.

New Clinical Nurse Specialist appointed in South East Scotland

Lynne Hunter has been appointed as a Mesothelioma UK Clinical Nurse Specialist and will be based at the Western General Hospital, part of NHS Lothian. Lynne will provide nursing care and support for mesothelioma patients in South East Scotland.

The post has been made possible thanks to funding from Scotland's asbestos, industrial disease and injury charity, Action on Asbestos.

Lynne will work with Mesothelioma UK Team Leader for Scotland, Carolyn MacRae, and will link with colleagues across the region to promote equitable access to mesothelioma specific support and treatment throughout the region. 50-60 cases of mesothelioma are diagnosed each year in the South East Scotland region.

In her new role, Lynne will focus on caring for patients with mesothelioma at every part of their treatment journey, helping to make their journey as smooth as possible. She will provide specialist support and advice to patients, families, healthcare professionals, and link in with local patient support groups.

Most recently, Lynne has worked as a pleural nurse at St John's Hospital in Livingston. Prior to this, she worked in general respiratory in St John Hospital.

Commenting on her new role, Lynne said: "I am really excited to be taking on this new role and bringing my previous experience in respiratory nursing practice. I have always had a strong interest in this area of nursing and have described the role as my dream job and it's finally great to get started."

Lorraine Creech, Head of Nursing for Mesothelioma UK, added: "Mesothelioma UK is extremely grateful to Action on Asbestos who have provided the funding for this post and are now working closely with Mesothelioma UK to support and complement the work of the Scottish National Mesothelioma Network. Lynne is a very valuable addition to the Mesothelioma Nursing Service for South East Scotland and the Scottish Mesothelioma Network as a whole.

"Lynne's appointment sees Mesothelioma UK reach 33 Clinical Nurse Specialists and seven within Scotland, providing dedicated care, support and treatment for mesothelioma patients throughout the UK."

Profile: Action on Asbestos

Action on Asbestos
Industrial Injury & Disease
(Formerly Clydeside Action on Asbestos)

Action on Asbestos has generously supported Mesothelioma UK with funding for Lynne Hunter's new Clinical Nurse Specialist role in Scotland.

Action on Asbestos is Scotland's leading asbestos, industrial disease and injury charity, providing practical and emotional support to those affected by mesothelioma, lung cancer and all other asbestos and work-related disease and injury. Its services are free to anyone in Scotland diagnosed with asbestos or industrial disease or injury, regardless of where you live.

For more than 35 years, it has been providing free and confidential information, advice, practical assistance and emotional support to anyone affected by an asbestos disease and now, has extended its services to help those with other industrial disease or injury. Each year, the charity's specialist welfare rights team assist more than 750 individuals and their families to recover millions of pounds in benefits and compensation that they are rightly entitled to.

For more information on Action on Asbestos, visit www.clydesideactiononasbestos.org.uk

ARMED FORCES

Anonymous donation boosts memorial fundraising

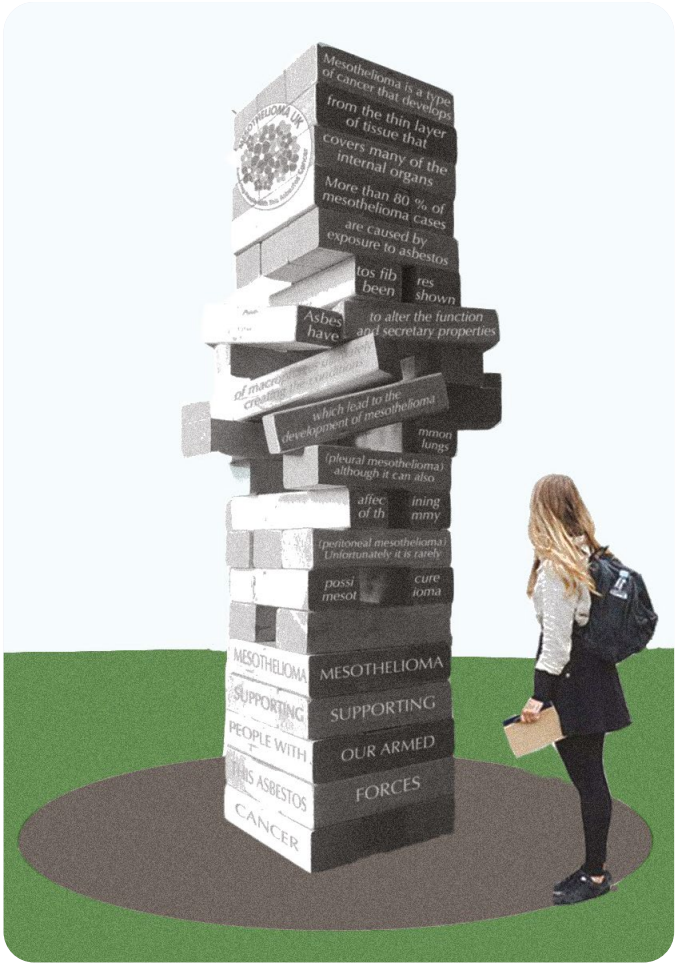
Mesothelioma UK – Supporting our Armed Forces has received a generous anonymous donation to the value of £15,000 to help create a new memorial.

The 'Mesothelioma UK – Supporting our Armed Forces' memorial is a unique concept depicting the building blocks of life, engraved with vital awareness information about mesothelioma, asbestos and our Armed Forces.

We want the families and friends of those affected to be able to visit the memorial and pay their respects or celebrate a key milestone. Let's keep all these memories alive.

We're looking for your support through donations as this will help us to create and build the memorial, and one day bring together family, friends and donors to remember our heroes.

The 'Mesothelioma UK – Supporting our Armed Forces' memorial will be made up of over 60 blocks. Our target is £40,000 and we're thankful to everyone who has donated so far. The sooner we can raise the funds the quicker we can have the memorial made.



We're accepting donations from as little as £10, right up to sponsoring a block for £500. You can support the creation of the new memorial by:

- Sponsoring a block at £500 each or a number of blocks
- Donating any amount to help us reach our target

To donate, please call our helpline or visit www.mesothelioma.uk.com/armed-forces-memorial-donation/

Mesothelioma UK Celebrates Armed Forces Day 2021

Mesothelioma UK – Supporting our Armed Forces is hosting a webinar on Thursday 24 June 2021 at 4pm to celebrate Armed Forces Day 2021.

Event attendees will find out more about the project, outcomes from the mesothelioma and the armed forces study and have the opportunity to hear about the Mesothelioma UK – Supporting our Armed Forces sculpture planned at the National Memorial Arboretum.

Speakers will include Liz Darlison, Mesothelioma UK CEO and Mesothelioma UK Clinical Nurse Specialist, Anne Moylan. We're delighted that Stephen Morgan, MP for Portsmouth South will be speaking at this event.

Register for this webinar by going to the 'Events' section of the Mesothelioma UK website.

Study update - armed forces, mesothelioma and carers

Virginia Sherborne from the Mesothelioma UK Research Centre at the University of Sheffield has now completed interviews for her PhD study where she has been interviewing the partners/carers of British military veterans with mesothelioma to find out about their experiences.

Virginia is now busy analysing the insightful information provided and data.

Armed Forces Action Mesothelioma Day 2021 Pack

With Action Mesothelioma Day 2021 being a virtual event this year, we still want to celebrate this special day with you!

You can order a special armed forces pack in the lead up to Action Meso Day 2021, which consists of a paper dove for you to write your special message on and to hang in a place of your choice, a branded Mesothelioma UK pen and a selection of armed forces branded items including a teddy, lapel pin badge, wristbands and stickers.

Visit our online shop to purchase this pack.

FUNDRAISING

Nick Maskell's Cycle Challenge

Our new Chair of Trustees, Professor Nick Maskell set himself a huge challenge for our #FitnessFebruary campaign – and raised a huge £7,027!

Nick decided to cycle 874 miles during February - the same distance as cycling from John O'Groats to Land's End.

On his Just Giving page Nick set up the ride by saying: "I have just taken over as the Chair of Trustees for Mesothelioma UK and wanted to mark this with a charity cycle ride to raise money for this great charity. I plan to cycle 874 miles during the month of February. This will be done whilst working full time at North Bristol NHS trust...I will therefore be getting the miles under my belt by cycling to and from work and topping it up on my Peloton bike. I will need to average 31 miles a day to achieve this."

We shared Nick's progress on our Facebook page and he managed to complete the challenge in just 26 days.

Many thanks to Nick for taking on the challenge and thanks to the wonderful supporters who were so generous with their donations.

Fitness Feb Re-Cap

Our annual Fitness Feb campaign took place in February 2021 and was a huge success! Our supporters raised an incredible £14,816.83.

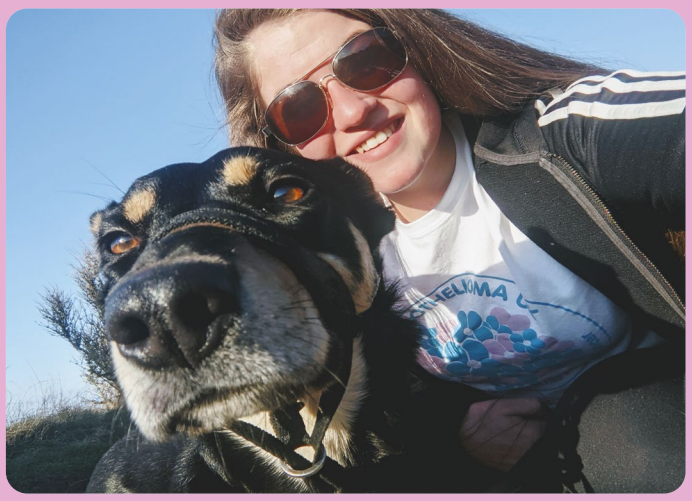
Sian Stone

Sian Stone from Acorn Analytical Services also took part in our Fitness February Campaign. "In the end I raised £740 and not only did I complete my original target of running 50 miles in February, but I then set another target to run 100km by the end of Feb (62.1 miles)! It was hard work some days, but some days were great, and I really enjoyed it. Proud to have raised that much money for Mesothelioma UK!"

Julie Heal

My sister and I took part in the fitness fab campaign and thoroughly enjoyed it and raised lots for Mesothelioma UK. We are really looking forward to fundraising more in the future.

Georgie Dean - In memory of Alistair Hutcheson, 1934 - 2020



My Granda was a plumbing and heating engineer, starting his apprenticeship when he was just 14 years old. After completing his apprenticeship and working for another firm, he then went on to start his own very successful business in 1961, which is still trading and will turn 60 years old this year!

He was the hardest working man I knew and worked every possible hour, taking such pride in the work he did. He was a true inspiration and was living proof that if you work hard in life you will get what you want out of it.

Sadly, in November 2019, my Granda was diagnosed with mesothelioma. I had never heard of this type of cancer before, but when I discovered that there is no current cure for mesothelioma it absolutely broke my heart. My Granda was so positive throughout his illness however, and always said that he was actually quite lucky, for he was able to live a good life prior to his diagnosis aged 85 years old and continued to live a good quality of life through most of his illness.

He was able to live to a fantastic age and his outlook on life and his illness was so inspirational. I will always remember one of his most used sayings - 'keep your pecker up', which he would even say to the nurses as they were leaving him following his routine at-home visits.

We sadly lost a lot of crucial time with Granda, for he was diagnosed a few months prior to the coronavirus pandemic. Not being able to see him in person was hard, however there were lots of waves through the window and plenty of phone calls we could always rely on!!

Sadly, a year on from Granda's initial diagnosis, his health started to take a noticeable decline. He always protected his loved ones as much as he could from the realities he was facing, however he could no longer hide what he was going through. I'll never forget him holding my hand one day, telling me that everything was going to be okay. Despite the pain he was going through, he still comforted me even during his final days. My Granda passed away in the early hours of Christmas Eve in 2020, peacefully with his family around him.

I was extremely close with Granda - from helping with homework after school, to helping me build my first igloo or teaching me how to drive, he taught me so much in life and he will always be loved and dearly missed beyond words.

Watching what my Granda had to go through made me think of how I would never wish it upon anyone else or their family to have to go through the same experience, which is why I decided to take part in #FitnessFebruary4Meso by walking 5K a day as I knew first-hand how the money would help others. Despite the difficult weather we had (lots of snow and wind!!) and my feet being in agony I continually thought of my Granda which got me through the challenge. I think raising awareness of mesothelioma is so important, as during my Granda's era the dangers of asbestos were not known.

Although sadly my Granda wasn't here to see my fundraising efforts, I know he will be watching down somewhere and hope I have done him proud. To all those suffering from Mesothelioma or their families, you are in my thoughts and my heart goes out to you all. In the words of my late Granda, throughout the difficulties, keep your pecker up. :)

Including Gift Aid, Georgie raised a fantastic £753.75.

Project Wales donation

Mesothelioma UK is extremely grateful for Thompsons Solicitors' generous donation of £2,000 as a contribution towards Project Wales. Amanda Jones, partner at Thompsons Solicitors said: "The work Sarah Morgan (Mesothelioma CNS) does for the mesothelioma patients and their families in Wales is amazing and I hope that this small donation will help Mesothelioma UK achieve their vision as set out in the project."

Move for Meso

Our annual #MoveForMeso campaign is back! Take part in our virtual event and get moving any way you like! Choose your challenge and get active between June and September. If you raise £150 or more, we'll send you a free Mesothelioma UK cap! Sign up today and get your fundraising pack! https://mesothelioma.enthuse.com/cf/move-for-meso

Online shop

We have plenty of items for all occasions on the Mesothelioma UK online shop! From charity balls to coffee mornings, we have something for every event! Check out our online shop today at www.mesothelioma.uk.com/shop/

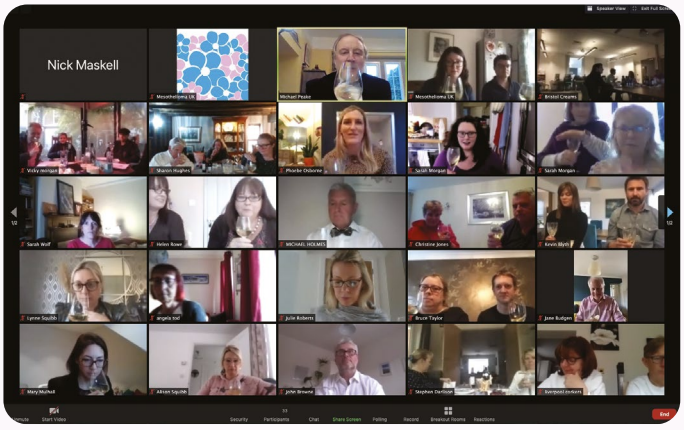
Wine tasting fundraiser

May saw Mesothelioma UK host its first wine tasting fundraiser. The event was held online and we were delighted to be joined by over 40 guests for a fun and informative evening.

Professor Mick Peake, trustee and ex-chair, was our wine expert for the evening, having been a member of The Wine Society for almost 50 years.

Four bottles of quality wines were delivered to guests ahead of the meeting and Mick shared his wealth of knowledge about each one while guests enjoyed tasting them in their homes. There was also a quiz and a raffle with some great prizes, sponsored by members of our legal panel.

The event was enjoyed by everyone and raised a fantastic £2,000. Thanks to everyone who joined us and/or bought raffle tickets and a special thank to our legal panel for their sponsorship of prizes.



Chris donates £5,000 after settlement

Chris Dacre was diagnosed with mesothelioma at Papworth Hospital in March 2020 at the age of 77. In the early 1970s he had worked as a carpenter in Peterborough for a company which manufactured temporary prefabricated classrooms for schools – asbestos was used extensively in the production of them.

Chris travelled all around the country putting the classrooms together. Depending on what the unit was used for it would be lined with Asbestolux (insulation board). It was concluded that it was while carrying out this work that Chris was exposed to asbestos.

Chris consulted the industrial diseases team at Irwin Mitchell solicitors shortly after his diagnosis. The team brought a case against his former employer and settled it in 2021 after the company admitted liability.

Father of two, Chris wanted to donate £5,000 to Mesothelioma UK as he said it is an excellent charity that provides great support. He is extremely grateful for the support he has received from clinical nurse specialist, Kate Slaven.

Chris said: “When I was first diagnosed, it came as a huge shock as I always felt like I had been relatively healthy.

“Over the past year, my condition has deteriorated, but the support from everyone, particularly Mesothelioma UK, has been amazing. It’s an excellent charity and I’m so grateful for the help provided by my local mesothelioma nurse. That’s what made me want to give something back to them, to say thank you.

“None of this would have been possible without Kate who is always there and always makes time for me and to answer my questions.

“I really wanted to share my story as there are still so many people out there unaware of the dangers of working with asbestos. And while there is nothing I can do to change my situation, I really can’t fault the support I’ve had; I’m very fortunate in that respect.”

Royds Withy King are Moving It For Meso

The Industrial Disease Team at Royds Withy King were Moving It For Meso in February and March. The team took part in a month-long challenge of various activities, from 15 February to 15 March, with a target of achieving two million steps, to raise funds for Mesothelioma UK.

The weather was iffy but spirits high as we went into this challenge. Some of the team got their running shoes on and went for daily runs, finding this the best excuse to get out and do some cardio. Other team members went for long walks after a workday. Some even did home workouts to up that step count!

For some, the challenge highlighted the importance of getting outside and remaining active during the COVID lockdown. It is so easy to slip into a routine during this pandemic and this challenge really got us motivated and focused on our mental wellbeing, as well as getting in those all-important steps.

Everyone in the team was fantastically involved and we smashed the target, having reached over 2.4 million steps as well as beating our fundraising target! A total of £545 was raised through JustGiving for Meso UK.

The challenge received a lot of support on social media and the team here at Royds Withy King are proud to have been involved in raising awareness and fundraising for this wonderful charity.

We look forward to getting involved with many further events with Mesothelioma UK this year!

Ambassador update

Our Mesothelioma UK ambassador, Brian, recently sent us an update on the work he and his colleagues at the newly formed East of England Asbestos Patient Support Group (EEA-PSG) have been doing.

The group held a virtual Muffins4Meso event in May at their temporary base, Copley Hill Management /Training Centre. Mesothelioma UK nurse Specialist, Kate Slaven attended as guest of honour. Patients, carers and volunteers met up online and donated cakes to staff at the Royal Papworth Hospital.

£406.00 was raised towards the Norfolk/ Suffolk Mesothelioma UK Clinical Nurse Specialist Fund and the Mesothelioma UK national Armed Forces mesothelioma memorial.

Grateful thanks to Judith and the management of Copley Hill for facilitating this first hybrid event for the group and for their kind donation.

Fundraising reaches the £20,000 milestone

The campaign to raise funds for a Mesothelioma UK Nurse Specialist in Norfolk or Suffolk reached a milestone in March when the fund exceeded £20,000.

The Anglia Asbestos Disease Support Group, made up of patients, carers, supporters and volunteers alongside Brian Wallis, Ambassador for Mesothelioma UK and representatives of Ashtons Legal, embarked on a fundraising campaign back in 2019 to contribute towards a specialist nurse in either Norfolk or Suffolk who would be employed by Mesothelioma UK.

There are currently just two specialist nurses based in the Eastern region - one at the Royal Papworth Hospital in Cambridge and the other at Broomfield Hospital in Chelmsford.

Not having a mesothelioma nurse in Norfolk or Suffolk means many sufferers living in those areas have a very difficult, and sometimes impossible, journey to get the specialist nursing support they need.

It costs approximately £60,000 to fund a Mesothelioma UK Nurse Specialist for two days per week, over a two-year period.

Ashtons Legal acts for many clients whose historic exposure to asbestos caused irreversible damage to their lungs and ultimately their death. They help clients and their families identify where that exposure took place and under a number of legal acts such as the Pneumoconiosis etc. (Workers Compensation) Act 1979 and the 2008 Diffuse Mesothelioma Scheme, bring a legal claim for compensation.

To donate towards the Mesothelioma UK Nurse Specialist fund for Norfolk or Suffolk go to www.justgiving.com/fundraising/anglia-asbestos-disease-support-group

Team challenge in memory of pleural nurse

Jen, a Pleural Specialist Nurse at Wythenshawe hospital is organising a fundraiser for Mesothelioma UK in memory of good friend and colleague Susan Jackson, also a pleural nurse, who died in a tragic accident in 2020.

On 25 July, several members of the pleural team and others, including our own nurses Lorraine Creech, Mairead Dixon and Lisa Clarke will take part in the Cheshire Sprint Triathlon.

On her Just Giving page Jen said: “This Just Giving page is to raise money for Mesothelioma UK in memory of our good friend and colleague Susan Jackson.

“This time last year Sue convinced me to take part in a Sprint Triathlon. She had done it before and really wanted to do it again. To be honest I wasn’t so keen, but after a lot of work she managed to persuade me. Unfortunately, we lost Sue in a tragic accident last August whilst she was out training for a different event.

“I decided that I still wanted to complete the Sprint Triathlon in her memory and have since managed to build quite a team who all want to help raise money in Sue’s name. Please help up raise as much money as possible for Mesothelioma UK- a charity Sue was very passionate about.”

The team will take on the Cheshire Sprint Triathlon on 25 July. You can support the team by donating at their MFT Pleural Team Just Giving page at www.justgiving.com/fundraising/mftpleuralteam.

Abby & Evie's half marathon walk

Abby and Evie met through their love of swimming and wanted to do something to raise money in memory of Abby's grandad who passed away nearly five years ago. Abby and Evie completed a half marathon walk and including gift aid raised an incredible £1063.75! Amazing work and all their family and friends are very proud of them!

Claire Almond does 100 burpees per day!

In March, I committed to 100 burpees per day throughout the whole month. In 2010, my father passed from mesothelioma. To mark 10 years after his death in 2020, I did a Facebook birthday fundraiser, from which I received £420 in donations, so in 2021 I set up another, but this time I wanted to do something for the donations! Hence 100 burpees per day! It wasn`t the easiest of challenges and there were days when I didn't want to do them. I also enlisted my friend to join in and between us we raised just short of £1,000!

Lottery

Don't forget Mesothelioma UK has launched a lottery! Tickets are just £1 to be entered into the £25,000 jackpot draw, so grab your tickets today to support Mesothelioma UK and be in with the chance to win!

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.

Events Calendar

June-September
Move for Meso campaign
Choose your challenge and get active.
info@mesothelioma.uk.com

24 June 2021
Armed Forces Day celebration webinar, 4pm
www.mesothelioma.uk.com/events/webinars/

26-27 June 2021
Cotswold Way Challenge
www.ultrachallenge.com/cotswold-way-challenge/

28 June 2021
Research Prioritisation Webinar, 4pm
www.mesothelioma.uk.com/events/webinars/

2 July 2021
Action Mesothelioma UK Day national event
www.actionmeso.org/amd21/

2-4 July 2021
Peak District Challenge
www.ultrachallenge.com/peak-district-challenge/

6 July 2021
Facebook Live Q&A, 11am
www.facebook.com/therealmesouk

10-11 July 2021
Isle of White Challenge
www.ultrachallenge.com/isle-of-wight-challenge/

26 July 2021, 4pm
Living Well with Mesothelioma webinar
www.mesothelioma.uk.com/events/webinars/

14 July 2021
Carers Hour webinar, 2pm
www.mesothelioma.uk.com/events/carers-hour/

17-18 July 2021
Yorkshire Challenge
www.ultrachallenge.com/yorkshire-challenge/

24-25 July 2021
South West Coast2Coast
www.ultrachallenge.com/coast-2-coast/

1 August 2021
London Landmarks Half Marathon
jill.lemon@mesothelioma.uk.com

3 August 2021
Facebook Live Q&A, 11am
www.facebook.com/therealmesouk

7-8 August 2021
Isle of Man Festival Challenge
www.ultrachallenge.com/isle-of-man-challenge/

11 August 2021
Legal Claims and Putting Affairs in Order webinar for carers, 2pm
info@mesothelioma.uk.com

22 August 2021
London Vitality Big Half Marathon
jill.lemon@mesothelioma.uk.com

Please send details of any local events to meso@sandstarcomms.com so that they can be added to the Mesothelioma UK website.

Many thanks to our Mesothelioma UK Legal Panel supporters

irwinmitchell
royds withy king
lawyers ahead of the curve
THOMPSONS SOLICITORS
STANDING UP FOR YOU
fieldfisher
Slater Gordon Lawyers
HUGH JAMES
Leigh Day
NOVUM LAW
NOVUMLAW.COM