MESOTHELIOMA MATTERS

Spring Edition 2023

MESOTHELIOMA UK

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Don't Let the Dust Settle campaign launched

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News

‘Don’t Let the Dust Settle’ campaign launched

Mesothelioma UK has launched a new ‘Don’t Let the Dust Settle’ campaign to call time on asbestos by raising awareness of the dangers of asbestos exposure and the asbestos-related cancer, mesothelioma.

The campaign focuses on sharing information about asbestos and mesothelioma. It was launched on 3 April 2023 to coincide with Global Asbestos Awareness Week from 1-7 April.

For more information on the campaign and to find out how to show your support, visit www.mesotheliomauk.com/dontletthedustsettle or follow and share the social media posts on Mesothelioma UK’s Facebook, Twitter and Instagram pages.

Nick Maskell, Chair of Mesothelioma UK and Professor of Respiratory Medicine at University of Bristol commented: “It’s very difficult to have to tell a 50-year-old with a young family that his work during a summer whilst still at school is probably why he has developed mesothelioma. That there isn’t a cure, and his life expectancy is less than 12 months only makes the situation more devastating. The UK has the highest incidence of mesothelioma in the world with as many as 2,700 people diagnosed per year, illustrating that asbestos is a very real and present danger. We need to call time on asbestos because with a better plan to protect people, we know that mesothelioma is largely preventable.”

Jane Hunt MP for Loughborough said: “Our heavy use of asbestos in the past has left the UK with a painful legacy of suffering and fatal diagnoses. So, I am extremely proud to have the national Mesothelioma UK charity in my constituency, providing specialist care and support to patients and families affected by mesothelioma – a devastating cancer caused by exposure to asbestos. I will do all that I can to support their mission for a future without mesothelioma by calling time on asbestos. Together we will not ‘let the dust settle’ on this issue.”

SKC products help in the fight against mesothelioma

Recently, Mesothelioma UK CEO Liz Darlison visited SKC Ltd, a specialist in air sampling equipment including asbestos sampling and monitoring products.

SKC products are used to measure asbestos during the removal process, and Liz talked to staff members about mesothelioma and how it is caused by asbestos. A spokesperson for SKC Ltd said: "SKC is pleased to support Mesothelioma UK and we were delighted that Liz came along to talk to all our employees so that they would gain a greater appreciation of the consequences of exposure to asbestos, where we as a company fit in, and 'why we do what we do'.

"We are aware how SKC and mesothelioma are at opposite ends of the asbestos situation and are proud that our equipment is able to help reduce the number of people in the future, that are so badly affected that they need the help of Liz and her team across the country."

Global Asbestos Awareness Week

From 1-7 April 2023, it's Global Asbestos Awareness Week, a worldwide annual event to raise awareness about the continuing presence of asbestos and the dangers of its exposure.

Whilst, in the UK, the importation and use of asbestos was banned in 1999, we need to ensure that people don't forget that it remains in many of our buildings, and the risk to health that this poses.

Asbestos exposure is responsible for 9 out of 10 mesothelioma cases, and we see up to 2,700 deaths in the UK ever year.

Mesothelioma UK is the largest information provider on mesothelioma. During Global Asbestos Awareness Week, please share our social media posts to help spread awareness. We will be sharing plenty of impactful content and stories from those

who have been affected by mesothelioma. We will also be asking people to get involved with our campaign to get the Government to commit to a programme of asbestos removal.

To get in touch or to find out more information contact 0800 169 2409, email support@mesothelioma.uk.com and follow us on Twitter @Mesouk.

Achieving equity in treatment and support for peritoneal mesothelioma

Sam Westbrook

Peritoneal mesothelioma is a rare cancer with around 130 new cases diagnosed each year in the UK.

Peritoneal mesothelioma (PM) causes the peritoneum to thicken and ascites to collect in the abdomen, causing swelling. Patients present with vague non-specific symptoms such as abdominal distension and pain which makes it difficult to diagnose. Patients with PM are being managed in a variety of oncological, medical and surgical specialities. It is important that the patient understands their rare cancer – knowledge of symptoms, outcomes, treatment options and treatment side effects.

The Peritoneal Malignancy Institute (PMI) at Hampshire Hospitals in Basingstoke facilitates a PM National Multi-disciplinary Team (MDT) meeting, which was established in 2016. The aim of the MDT is to discuss and plan the management of all patients with a confirmed diagnosis of peritoneal mesothelioma.

The MDT comprises of a team of clinicians dedicated to improving outcomes for patients affected by peritoneal mesothelioma. These include peritoneal malignancy surgeons, specialist radiologists, specialist nurses, histopathologists, and oncologists with an interest and experience in PM.

The MDT aims to enable equitable access to treatment including clinical trials and carefully selecting cases for cytoreductive surgery and hyperthermic intraperitoneal chemotherapy.

Since 14 July 2022, PM patients have been able to access first line combination immunotherapy with Ipilimumab and Nivolumab on the NHS.

Sam Westbrook, the nurse specialist based at PMI and funded by Mesothelioma UK, works to improve support for the patient and their family/carer.

It is important for healthcare professionals to refer PM cases to the MDT so that we can achieve treatment and support equality.

“Peritoneal mesothelioma patients should have the opportunity for their case to be reviewed by specialists in this area of rare cancer. By doing this, we can ensure patients are well informed and empowered to make decisions about their care,” commented Sam, peritoneal mesothelioma clinical nurse specialist.

There is a specific online virtual support group for PM patients and their family. They can attend to connect with others going through the same experience. The dates and information on how to attend is on the website at www.mesothelioma.uk.com/peritoneal-support-group.

“Talking to others has given us a broader insight of what really goes on. When we started this journey with peritoneal mesothelioma, it was quite daunting thinking you were ‘on your own’ but that has now passed,” said a patient.

“The online support group is a friendly and supportive group of patients who have the something in common. They encourage each other and offer their experiences to those in need. I am on hand to provide advice, but the group mainly enjoy talking and listening to each other,” added Sam.

Building evidence on asbestos in public buildings

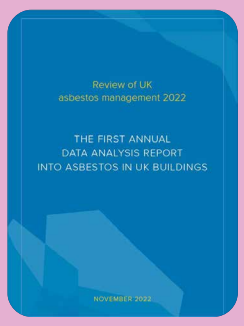
The Asbestos Testing and Consultancy Association (ATaC) and the National Organisation of Asbestos Consultants (NORAC) presented their first annual report on the condition of asbestos in UK buildings to members of Parliament in November 2022.

It was a response to the Parliamentary Work and Pensions Committee inquiry into the Health and Safety Executive (HSE's) approach to asbestos management.

The report is the first time that any organisation has attempted to collate and analyse a large body of data regarding asbestos in UK buildings, with over 1 million lines of data, derived from over 120,000 asbestos surveys undertaken between October 2021 to March 2022.

You can view a copy of the report on ATaC's website at www.atac.org.uk.

This was the first collaborative effort between these two trade bodies and represents a significant step forward in industry co-operation. Mesothelioma UK is now working with ATaC and NORAC to help them to build further evidence on the current extent and condition of asbestos in UK buildings.



John Richards, Managing Director of Thames Laboratories and a former chairman of ATaC said: "We're engaging with Mesothelioma UK in an effort to produce evidence to advocate further changes to regulations and guidance. Over the coming months, we hope to formalise this more.

"At the moment, we are working within our sector to bring more organisations on board to scale up the quantity of data that we have, while at the same time, looking at what additional data we could collect to allow better segmentation and assessment of risk within differing types of premises.

"As the report states, this is the first time that this has been attempted. In the first report, we collected data from 20 organisations – we now have commitment from an additional 40 and are targeting 100 organisations.

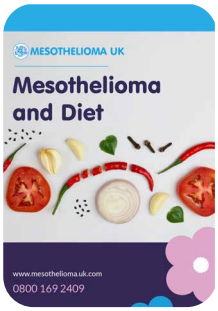
"We are currently in the early stages of working with the University of Wolverhampton to identify sources of fundings to allow them to undertake an independent analysis of the data and turn the information into a fully-fledged academic research project."

New patient information on diet and mesothelioma

It is important for people to eat well when they have cancer. But it's not always easy. Our newly revised booklet is packed full of information, recipes and tips to help.

It includes general advice about maintaining a balanced diet, and specific guidance on eating difficulties such as bloating and loss of appetite. We've also included new sections on nausea, and support for families and carers who may be finding it difficult watching someone they care about struggle with eating.

Download a copy for free from: www.mesothelioma.uk.com/downloadable-resources.



Latest on Project Cymru/Wales

Sarah Morgan, Project Lead for Mesothelioma UK's Project Cymru/Wales

Mesothelioma UK Project Cymru/Wales was launched in October 2020 and is now at a transition point.

The original project analysis highlighted the significant scale of the challenge in Wales to ensure equity for all patients affected by mesothelioma. Much has been achieved and much is yet to be done, working across boundaries to deliver specialist services for all patients, regardless of where they live.

Project Cymru/Wales initiated and facilitated new discussions with NHS Wales and achieved agreement for dedicated funding to set up an All-Wales Mesothelioma Specialist Multi-disciplinary team (MDT). Plans are agreed for this to be set up within the first half of 2023. This MDT will ensure that all patients throughout Wales are discussed by the most experienced clinical professionals with specialist expertise in mesothelioma.

In addition, Project Cymru/Wales has secured funding for two new part-time Mesothelioma Clinical Nurse Specialist (CNS) posts for Wales. This has been achieved through a successful joint bid for funding with Macmillan Cancer Support Wales and Mesothelioma UK.

Expressions of interest inviting health boards to bid for the funding for these CNS posts have gone out.

The project has ensured increased support for, and engagement with, mesothelioma patients across Wales including regular patient and carer support group meetings, both face-to-face and remotely online, in partnership with AASC (Asbestos Awareness Support Cymru). Project Cymru/Wales continues to increase the distribution of information for patients and professionals across Wales, promoting the use of bilingual communications where possible, and collecting direct patient feedback and case histories to help amplify the patient's voice and raise awareness of the needs of patients with this rare cancer.

We have approximately 100 new cases of Malignant Pleural Mesothelioma (MPM) each year in Wales and approximately 2,500 new cases of lung cancer. These figures indicate that each MPM case is only one of every 25 lung cancer cases discussed in local MDTs, with some health board MDTs seeing fewer than 10 cases of MPM per year.

Experience indicates that a local approach only doesn't work in the interests of patients with rare cancers. Project Cymru/Wales is working towards developing a 'hub and spoke' approach to the delivery of mesothelioma services across all of Wales, working as a network, actively engaging with a wide range of individuals, groups and organisations to provide equitable high quality virtual and in-person services to patients in Wales.

We are looking forward to achieving some very exciting goals in 2023. The new hub and spoke approach includes a unified team of three Mesothelioma CNSs, an All-Wales virtual MDT, educational events and new research trials, and will help provide a full coverage service for all patients in Wales. This will encourage equity for all health boards and engage all specialisms needed to ensure delivery of equitable services for those affected by mesothelioma throughout Wales.

Project Northern Ireland targeting first nurse post

We've highlighted Project Northern Ireland in previous editions of Mesothelioma Matters, a campaign aiming to ensure that mesothelioma patients and their families in Northern Ireland have access to the best treatment, care and support available.

The campaign is being driven by the Rodgers family from Newry, Co Down, following the passing of their husband and father, Tony from the disease on New Year's Day in 2022. The family helped to host a quiz night in October 2022, raising over £8,000 for the Project Northern Ireland fund.

Mesothelioma UK is currently talking to a major hospital in Northern Ireland about hosting a new Clinical Nurse Specialist and will be applying for grant funding to support the role, with the aim of recruiting and getting the nurse in post over the spring/summer.

A committee will be established once the nurse is in post to oversee the Project Northern Ireland funding. A new section on the Mesothelioma UK website has been developed to showcase the campaign, how it can be funded and what the funding will support. See www.mesothelioma.uk.com/project-northern-ireland.

The project team was able to get several buildings in Newry and Derry lit up blue for Action Mesothelioma Day last year and are keen to engage more with the 'Go Blue for Meso' campaign in July 2023.

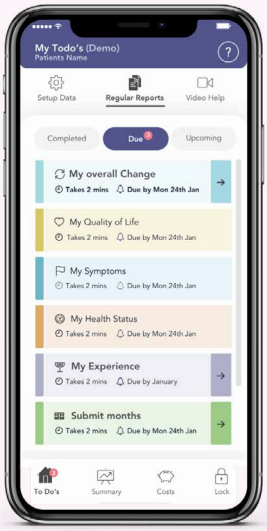
Health companion

Have you considered trying our digital Health Companion tool? In collaboration with DaSH Global, we developed a digital 'Health Companion' that enables patients to submit data about their quality of life and experiences in the management of mesothelioma, as well as any costs associated with the condition.

Patients are able to take more control in the management of their condition using the tool to record, monitor and communicate healthcare information, and 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 and enhance the nurse-patient communications. Health Companion managers will also be available to support the patients directly or via communications with the clinical nurse.

Visit www.health-companion.me for more information or contact the Health Companion Managers at hcmanager@mesothelioma.uk.com or by phoning 0116 218 5718.



Meso UK at iMig 2023

Representatives from Mesothelioma UK will be attending the 16th International Conference of the international Mesothelioma interest group (iMig 2023), to be held from 26-28 June 2023 in Lille, France.

iMig is the original and longest standing society dedicated solely to the study of mesotheliom,a and aims to be the central body promoting research, treatment and education for mesothelioma. In conjunction with The French Cooperative Thoracic Intergroup (IFCT), the event will offer workshops, plenary sessions, oral abstracts and poster sessions to stimulate ideas and establish research collaborations.

The multidisciplinary conference will bring together delegates from around the world and feature the most up-to-date research on diverse topics of interest.

Further information can be viewed at www.imig2023.org.

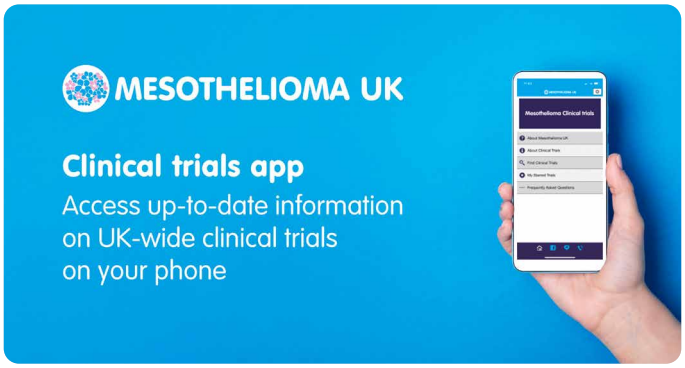
Clinical trials app provides information at your fingertips

Mesothelioma UK's clinical trial app is a universal mobile app for trial participants that makes their involvement in clinical studies more convenient and effective.

The app offers patients the information they need when considering participating in clinical studies.

The app includes basic information about current trials and where they are located, plus the capability to create a favourites list and more.

You can download the app for free from the Apple Store or Google Play or scan the QR code.



What do you want to see in this magazine?

SCAN ME

We are keen to ensure that the Mesothelioma Matters magazine offers our readers what they want.

To achieve this, we'd love you to fill in a short survey. It should take around 3-4 minutes to complete and will really help us to create content and stories that will be helpful to you. Scan the QR code or use https://forms.office.com/e/jC6RyHbjbG to fill out the survey.

If you would prefer to fill in a paper version of the survey, or have it emailed to you directly, please call 0800 169 2409 or email fundraising@mesothelioma.uk.com.

CEO visits asbestos monitor and detector manufacturer

Liz Darlison and Loretta King

Mesothelioma UK Chief Executive, Liz Darlison, recently visited Alert Technology Ltd, developer and manufacturer of the world's first and only range of real-time airborne asbestos monitor and detectors. Here's what Alert Technology had to say about the visit:

Alert Technology Ltd recently welcomed Liz Darlison, founder and CEO of Mesothelioma UK to their Devonshire office. Liz was given a tour of the facilities, introduced to the team and offered an overview of Alert's real-time airborne asbestos detection technology – designed specifically to reduce exposure to airborne asbestos.

Loretta King, MD of Alert Technology Ltd explained the passion behind their innovation: "Asbestos exposure is incredibly personal to us. About two years ago my father, Alan Archer who founded Alert Technology was diagnosed initially with pleural plaques and then subsequently with kidney cancer, both of which are directly the result of exposure to asbestos in his youth as an apprentice plumber. Very luckily for us, his conditions were treatable and following removal of one of his kidneys, he is healthy and cancer free.

"We will be forever grateful that his was not a mesothelioma diagnosis which often means survival of less than a year. My father always knew he'd been exposed in his youth and whilst his diagnosis was made long after we'd begun our journey to develop the Asbestos ALERT PRO, it has definitely cemented the importance of what we're doing here and how there has to be a better way to handle this risk."

Alert was honoured to spend a couple of hours with Liz, introducing her to Alan, and giving her a tour of Alert's office and manufacturing facility in Devon. Alert Technology is committed to supporting Mesothelioma UK and encourages others to do the same.

Long-term plan for UK cancer care

One Cancer Voice is a group of over 60 cancer charities, including Mesothelioma UK, collectively supporting millions of people living with cancer.

We want the Prime Minister to commit to taking action to dramatically improve the experience and outcomes of people affected by cancer.

In a speech at the Francis Crick Institute on World Cancer Day 2022 in February, the then Health and Social Care Secretary, Rt Hon Sajid Javid MP, declared 'a war on cancer' and launched a call for evidence to underpin an ambitious 10-Year Cancer Plan for England.

The call for evidence was the beginning of the process to inform the Government's 10-Year Cancer Plan, a new vision for how the UK will lead the world in cancer care. It promised to take a long-term look at how we harness innovation and what we want the patient experience to look like in 2032, with ambitious plans for action in several different areas. Over 5,000 people and organisations responded to that consultation.

On 24 January 2023, the Government announced that it will be launching a 5-year 'Major Conditions Strategy' – which means they will no longer be publishing a 10-Year Cancer Plan. We are concerned that this reflects a dilution of the ambition and shifts focus away from some of the specifics asks, issues and opportunities for cancer services and for people affected by cancer.

That's why, collectively, One Cancer Voice, has come together, on behalf of people affected by cancer, to hold the Government to account and ensure it does not retreat on its ambition to transform cancer care and services for patients now and in the future.

We want the Prime Minister to commit to taking action to dramatically improve the experience and outcomes of people affected by cancer.

We are calling on the UK Government to put the needs of cancer patients first:

- To make sure the cancer elements of the upcoming Major Conditions Strategy are ambitious, fully funded and inclusive of the voices and evidence from the cancer community
- To commit to a longer-term strategy for cancer which focuses on transforming cancer research, diagnosis, treatment, and patient experience

The petition was launched on 7 February – you may have seen it on our social media channels – and was live for four weeks. It was handed in to the Prime Minister at No.10 on March 22 and we eagerly await his response.

Farewell to trustees

We're bidding a fond farewell to three esteemed colleagues on Mesothelioma UK's board of Trustees. Dr David Hetmanski, Professor Mick Peake and Sharon Hague are all stepping down from their roles in March. Dr Hetmanski has been a Trustee of Mesothelioma UK since 2010 and Sharon Hague joined the board in 2018 after supporting her father through his mesothelioma journey. Professor Peake is a former Chair of Mesothelioma UK, having been involved in the development of national cancer policy since the mid-1990s.

Liz Darlison, Chief Executive of Mesothelioma UK said: "Mick, David and Sharon bring vast clinical and professional expertise and experience to our board, along with their respective personal passions. They have all been pivotal in helping to shape, direct and develop the charity over many years. Mick has been with us from the very start and helped to set up the charity in the early days, whereas David has a real focus on research which is a crucial element of our work and Sharon brings a personal perspective of the impacts of the disease.

"We thank them so much for all of their input and support; and hope that they will remain friends of Mesothelioma UK as we move onto the next stage of our development."

Experience and expertise

Dr. David Hetmanski

Dr Hetmanski was Deputy Director of Research & Innovation at University Hospitals of Leicester until retirement in 2021. With over 20 years' experience in research management, he was also chair of the East Midlands R&D Leads as well as holding an honorary position with the University of Leicester. Before moving into research management, David held a number of posts in the NHS and the university sector.

"My first meeting as a trustee took place in small office at Glenfield Hospital and now the charity has splendid headquarters of its own to support the important work for patients and carers, and funding research. It has been an honour and a privilege to be part of Mesothelioma UK."

Prof. Mick Peake

Professor Mick Peake was until very recently the Clinical Director of the Centre for Cancer Outcomes, University College London Hospitals, and remains a Specialist Clinical Advisor to Cancer Research UK.

He is also Emeritus Consultant and Hon. Professor of Respiratory Medicine in the University Hospitals of Leicester.

Professor Peake has had a major interest in lung cancer and mesothelioma for many years, establishing the National Lung Cancer Audit. He was heavily involved in the development of the National Cancer Registration and Analysis Service and was National Clinical Lead for Lung Cancer until the NHS reforms of 2013. He founded the UK Lung Cancer Coalition, is a member of the board of the British Thoracic Oncology Group and the National Lung Cancer Forum for Nurses.

Mick said: "Mesothelioma UK has been a big part of my professional life for 20 years and I am sad to leave the board. However, with Liz at the helm, a great management team and a very committed and experienced board, I know I leave it in excellent hands. It has been hugely successful in both raising the profile of mesothelioma in the UK and in improving patient care through its network of specialised nurses."

Sharon Hague

Sharon Hague is a Managing Director at Pearson plc, a leading global education company, where she has worked for over 20 years. She is responsible for the development and delivery of qualifications, assessments and teaching and learning resources in the UK and US.

In 2017, Sharon's father, Douglas Hague was diagnosed with mesothelioma having worked as a telecommunications engineer in London for nearly 40 years. Sharon supported her father throughout his illness until he passed away in August 2018.

Sharon commented: "Having had this experience with my father, I really wanted to help others and make a difference, which is why I joined the board of Trustees at Mesothelioma UK. During my time on the board, I've been incredibly impressed by the drive and sense of purpose of the team, and we've made some incredible advancements in the work of the charity including influencing and shaping policy, reaching out to the Armed Forces community, approval of immunotherapy and many more.

"We've also helped to identify and support other, more non-traditional groups of people who are affected by mesothelioma including healthcare workers, teachers and women. It's been a real privilege to be involved and I encourage everyone to continue to support the vital work that the charity does."

If you're interested in applying for a role as a Trustee of Mesothelioma UK, please contact the charity on 0800 169 2409 *or email* info@mesothelioma.uk.com.

Mesothelioma updates

UHL Clinical Librarian Service
"bringing you the evidence"

Newly published research in mesothelioma compiled by the University Hospitals of Leicester Clinical Librarian Services

Mesothelioma UK are delighted to include this regular addition to Mesothelioma Matters. In each edition any new publications in the preceding 3 months, the title, author and journal, will be listed. We hope you find this useful and thank you UHL clinical librarians!

New scientific research

Pleural manometry during thoracocentesis in patients with malignant pleural effusion: A randomized controlled trial
Hassaballa AS, Mostafa A, Hikal T, Elnori A, Elsayed HH.
Can J Respir Ther. 2023 Jan 20;59:33-44. doi: 10.29390/cjrt-2022-047

Alvopem® (pemetrexed) safety assessment in patients with non-small cell lung cancer or malignant pleural mesothelioma: a post-marketing surveillance
Seifi S, Salimi B, Monfared ZE, Sabahi C, Kafi H, Khosravi A.
J Pharm Policy Pract. 2023 Jan 25;16(1):16. doi: 10.1186/s40545-023-00524-5.

Serum diagnostic markers for malignant pleural mesothelioma: a narrative review
Wang JJ, Yan L.
Transl Cancer Res. 2022 Dec;11(12):4434-4440. doi: 10.21037/tcr-22-2873.

Immune checkpoint inhibitors in malignant pleural mesothelioma: a systematic review and meta-analysis
Gemelli M, Cortinovis DL, Baggi A, di Mauro P, Calza S, Berruti A, Grisanti S, Rota M.
Cancers (Basel). 2022 Dec 9;14(24):6063. doi: 10.3390/cancers14246063.

Sensitivity and complications of thoracentesis and thoracoscopy: a meta-analysis
Martinez-Zayas G, Molina S, Ost DE.
Eur Respir Rev. 2022 Dec 21;31(166):220053. doi: 10.1183/16000617.0053-2022. Print 2022 Dec 31.

The clinical utility of the LENT score in patients with malignant pleural mesothelioma
Söyler Y, Kavurgacı S, Gürel Akan E, Yılmaz Ü.
Tuberk Toraks. 2022 Dec;70(4):341-348. doi: 10.5578/tt.20229605.

Multimodal therapy of epithelioid pleural mesothelioma: improved survival by changing the surgical treatment approach
Klotz LV, Hoffmann H, Shah R, Eichhorn F, Gruenewald C, Bulut EL, Griffo R, Muley T, Christopoulos P, Baum P, Huber P, Safi S, Kriegsmann M, Thomas M, Bischoff H, Winter H, Eichhorn ME.
Transl Lung Cancer Res. 2022 Nov;11(11):2230-2242. doi: 10.21037/tlcr-22-199.

Qualitative studies and patient experience

Psychosocial well-being among patients with malignant pleural mesothelioma
Demirjian CC, Saracino RM, Napolitano S, Schofield E, Walsh LE, Key RG, Holland J.
Palliat Support Care. 2023 Jan 19:1-5. doi: 10.1017/S1478951522001596. Online ahead of print.

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

12

Can you share your story?

We're currently interviewing patients and carers about their mesothelioma experience and stories.

We want to reflect the range of people affected by mesothelioma. For example, we'd be keen to hear from people under the age of 50, or perhaps people from professions such as teaching or nursing.

All of your thoughts, observations and stories can really make a difference, so please help us to raise awareness of mesothelioma by sharing them.

If you would like to help, please email fundraising@mesothelioma.uk.com or call 0800 169 2409.

Alternatively, if you would like to share your story by filming it yourself and sending it to us, you can find a step-by-step guide at www.mesothelioma.uk.com/share-your-story.

Research

Coroner experiences project

The Mesothelioma UK Research Centre in Sheffield is working on a small research project to find out about UK families' experiences of coroners' inquests (or procurator fiscal investigations).

The project is looking at the differences across the UK in coronial procedure when it comes to mesothelioma cases and the impact it has on patients' families.

Researchers will use a survey and interviews to explore positive and negative aspects of peoples' experiences, and aims to use the findings to improve experiences during this difficult time.

The study is currently in the research phase and the team has been speaking to various professionals who are involved in the process and with whom families might have contact. The initial findings show that the procedure varies widely across the UK which causes uncertainty for everyone involved.

Keep an eye on the Mesothelioma UK Research Centre website for future updates at www.sheffield.ac.uk/murc.

Mesothelioma UK Research Centre Sheffield - update

It has been a busy few months at the Mesothelioma UK Research Centre. We summarise some of our key activity.

Following the completion of our study on palliative care in mesothelioma, we have published a new study which explores palliative care roles and responsibilities of mesothelioma clinical nurse specialists in the UK, and highlights the vital role they play in providing palliative care (Gardiner 2022). We have also been working hard to share our animation which demystifies palliative care, and our infographic for health professionals, both of which can be found on our website.

We have completed data collection for our study, exploring variability in the patient experience of peritoneal mesothelioma and have collected a range of data from patients, family members, health professionals and support workers. We are now undertaking analysis in collaboration with Sam Westbrook and the team at Hampshire Hospitals NHS Trust. We hope to be able to share preliminary findings within the next few months.

We have recently published a journal article from our MEWS study which is exploring experiences of presentation, diagnosis, treatment and care for current and former school-based education workers with mesothelioma (Taylor 2022). The article highlights the lack of research in this area and the importance of tackling asbestos in schools and can be found here: www.sheffield.ac.uk/murc/our-research.

The MINNOW study, which explores the mental health and well-being impacts of mesothelioma on patients and their loved ones, is now at the data analysis stage. We would like to thank everyone who helped with recruitment and those of you who kindly took part in the questionnaire and interviews. We are looking forward to sharing our findings later this year. We are really hoping that this work will make a positive difference to individuals and families living with mesothelioma.

Our PhD student, Emilie Couchman has been collecting data for her PhD study on continuity in primary care for people with mesothelioma. Emilie also published a recent article on her personal experiences of being an academic researcher whilst also working as a GP. You can read the article here: https://bjgplife.com/fragmented.

We were delighted that our entry to the 2022 Mesothelioma Christmas Carol Off was voted winner in the 'best vocal harmony' category! We were very grateful to the Sheffield University SingSoc for helping us out and providing superb backing vocals which clinched the win.

Finally, we would like to thank everyone who has participated in, or collaborated on our research. Without your help and support we would not be able to generate the evidence or impact from our work.

References:

Gardiner C, Harrison M, Hargreaves S & Taylor B (2022) Palliative care roles and responsibilities of mesothelioma clinical nurse specialists in the UK, Progress in Palliative Care, DOI: 10.1080/09699260.2022.2158286

Taylor B, Allmark P, Tod A (2022) The Experiences of Presentation, Diagnosis, Treatment and Care for School-Based Education Workers with Mesothelioma: A Scoping Review. Int J Nurs Health Care Res 5: 1342. DOI: 10.29011/2688-9501.101342

Supporting our supporters

The Mesothelioma UK Research Centre at Sheffield is launching a new research project to find out about the needs of people caring for or supporting a relative or friend living with mesothelioma.

Unpaid informal carers play a vital role in day-to-day support for people with mesothelioma, and yet their needs may not be understood or addressed.

The new research project aims to find out how needs change over time, what helps people in their caring role, and what are the gaps. The project aims to improve support for family and friends.

Who can take part?
To take part in the research project you need to be providing unpaid help to a relative or friend needing support due to mesothelioma; be an adult (18 years plus); and live in the UK. You may live with the person with mesothelioma, or elsewhere (either locally or at a distance).

What does taking part involve?
The research will involve filling out surveys about your experiences of caring and how needs change overtime.

We will also invite you to think about whether you would like to take part in interviews to talk about your experiences. This is optional. The interviews would be one-to-one with a researcher and would take place either online or on the telephone.

How to take part:
You can take part in the online surveys from the following link: https://shef.qualtrics.com/jfe/form/SV_0rmXFcOaxK1CQt0.

If you would prefer, we can send paper surveys through the post (ring Sarah on 0114 222 2406 to arrange this). Stamped addressed envelopes would be provided to return them.

If you have any questions, please do not hesitate to get in touch with the researcher: Sarah Hargreaves (email: sarah.hargreaves@sheffield.ac.uk, telephone: 0114 222 2406).

How pain affects those with mesothelioma

Dr Catriona Mayland

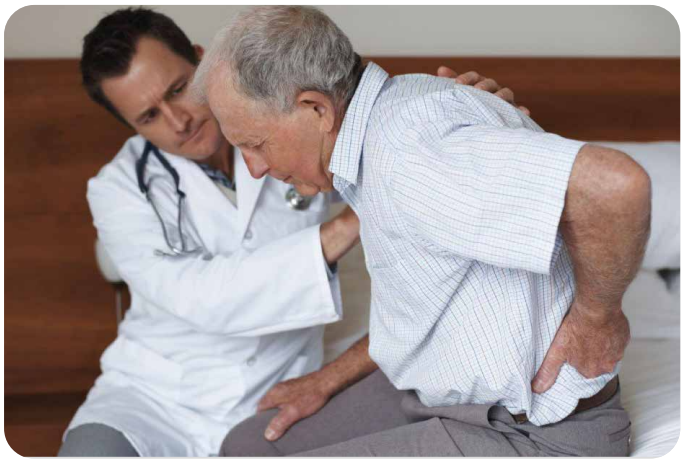
By Dr Catriona Mayland, Yorkshire Cancer Research (YCR) Senior Clinical Research Fellow & Honorary Consultant in Palliative Medicine, Principle Investigator for the 'Pain in Mesothelioma' study.

Patients with mesothelioma can develop a number of symptoms including pain. Sometimes the pain can be complex and variable in its severity and nature, due to the mesothelioma affecting the chest wall and the nerves. At present, it is hard to know which patients with mesothelioma develop severe pain, at what point during their illness, and who might need more support and interventions earlier to help control the pain.

As a sub-study of ASSESS-meso (Chief Investigator, Dr Anna Bibby), a national study examining the natural history of mesothelioma, we are focusing on learning more about the pain which affects those with mesothelioma. For example, we want to see if we can find out more about which patients develop pain, at what point during their illness, how severe the pain is, and what impact the pain has on patients' quality of life. Finding out this information will help us know when in a patient's illness the pain is more problematic and when we need to be more proactive in using more complex techniques to control the pain.

More than 100 patients have been recruited to the study. Follow-up will continue until November 2023. When we have the results, we will conduct an engagement event with those affected by mesothelioma (including their family members) to share the findings. We also wish to seek their opinion about how our findings should impact on clinical care and the next steps in terms of future research.

For more information visit www.sheffield.ac.uk/palliativeresearch/pain-malignant-pleural-mesothelioma or email Dr Mayland at c.r.mayland@sheffield.ac.uk.



Clinical trials

MITOPE trial brings a new class of cancer treatment to patients

RS Oncology, LLC, a U.S.-based biotechnical company focused on the treatment of patients suffering from mesothelioma or MPE, having initiated its MITOPE Phase 1/2 clinical trial in March 2022, has now administered over 40 doses of its novel drug, RSO-021, as part of the dose escalation phase of the trial.

In many circumstances, patients suffering from mesothelioma or Malignant Pleural Effusion (MPE) require the installation of an IPC to either drain the effusion fluid or to be used to administer talc in an attempt to cause pleurodesis in the patients.

However, with the advent of RSO's new therapy, patients should be screened and considered for participation in the MITOPE trial before the IPC drain is removed and before pleurodesis is attempted, especially in cases where patients have progressed from prior therapies as this new therapy can be given as a follow-on treatment.

MITOPE is a first-in-human Phase 1/2 clinical trial that brings patients a new treatment option. The RSO-021 drug targets a specific mitochondrial enzyme regulating oxidative stress, killing cancer cells while sparing normal tissues. RSO-021 is administered weekly locally into the pleural cavity using an IPC immediately after pleural effusion is drained.

Approximately 15% of solid tumour patients develop pleural effusion (excess fluid build-up in the lungs) as their disease spreads to the lungs. This condition is common among mesothelioma patients in particular.

MITOPE is open to patients who are at least 18 years old and have documented tumour progression after receiving at least one prior standard of care treatment at the following sites: the University Hospitals of Leicester and Oxford and the Guy's Hospital in London. RSO continues to work on expanding the number of available sites across the UK.

"Targeted therapies for mesothelioma have been lacking. RSO-021 spearheads a new generation of small molecules that could potentially improve patient outcomes by targeting a novel Achille's Heel in mesothelioma," said Professor Dean Fennell, Director of the Leicester Mesothelioma Research Programme.

"We are very excited to ramp up our efforts in recruitment and enrollment for eligible patients and, to ease the burden of treatment, RSO will cover out-of-pocket travel expenses for those on the trial," said Jarrett Duncan, RS Oncology CEO.

"We're pleased with the results so far and look forward to providing more geographically convenient sites for patients suffering from mesothelioma or MPE in the UK," added COO and Head of Business Development, George Naumov, Ph.D.

To learn more about the trial, please visit www.mesothelioma.uk.com/clinical-trials.

Update on the NERO trial

In July last year, the NERO clinical trial opened to mesothelioma patients.

This trial, run by Chief Investigator Professor Dean Fennell at the University of Leicester and the team at the CRUK Southampton Clinical Trials Unit, is testing whether a type of targeted cancer treatment could improve survival for people with mesothelioma.

The treatment being trialled in NERO is niraparib, a type of drug called a PARP inhibitor. PARP inhibitors work by blocking a protein which helps repair damaged DNA in cells. PARP inhibitors have already been shown to improve the survival of patients with breast and ovarian cancers that carry specific mutations. The NERO trial will look at whether niraparib can have a similar effect for mesothelioma patients.

The trial is aiming to recruit a total of 84 patients and, so far, 26 participants have joined the trial. These are patients with mesothelioma who have already had chemotherapy treatment. Participants are randomly allocated into one of two arms within the trial, either to receive niraparib or to continue with active symptom control, so that the researchers can compare the effect of the drug on the tumour. Patients have a 2:1 chance of being allocated to the arm where they will receive niraparib and those patients in the control arm will be closely monitored for signs of early tumour growth so that they can go on to receive an alternative treatment if necessary.

The trial initially began recruiting participants at the Leicester Royal Infirmary in July 2022. It has since expanded to six more sites across the UK, in Leeds, Southampton, Harlow, Taunton, Cardiff, and Hull, with further sites set to open in Medway, Glasgow, Sheffield and Belfast over the next few weeks.

An extremely important part of the initial design and conduct of any clinical trial is making sure that it is suitable and acceptable to the patients who will take part. The team at the Southampton Clinical Trials Unit, who manage the running of the trial, are therefore highly committed to involving patient and public representatives on trial committees. NERO has public members sitting on both the Trial Management Group and also the Independent Data Monitoring Committee, the group which is responsible for looking at all the incoming clinical data from participants during the trial to make sure there are no safety concerns for those taking part.

NERO is featured on the Mesothelioma UK app where anyone interested can find out more about the trial and how to take part. Patients who wish to take part in NERO should speak to their consultant to find out if they may be eligible, in which case their consultant can refer them to a hospital where the trial is currently open.

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.

You can watch an explainer video about the trial at www.youtube.com/watch?v=ARofdfv05l4

Legal panel

Patient story: Frederick Weeks

By Mark Luxton, Slater and Gordon

Mr Frederick Weeks worked as forklift truck driver for the Ministry of Defence at the Bedenham Armaments depot in Gosport from 1976 to about 1985.

Mr Weeks recalled being exposed to asbestos at work on a few occasions. Most unusually at the time he worked at the depot for many years, there were cows and even horses on the site who were 'employed' to eat the grass in the areas that workers at the depot were not allowed to walk on. The farmer who also worked there was engaged to move the animals to different areas around the site to keep the grass under control. The buildings on the site were heated by radiators fed by large pipes that came from the steam room and ran around the site to the various buildings. On occasions the workers at the site would stop and watch and talk about the cows who would tear their way through the plastic covering to be able to eat the asbestos lagging on the pipes. Dust clouds could be seen as the cows ripped their way through the asbestos lagging.

Mr Weeks was also exposed to asbestos when moving boxes around on the forklift truck which could bump across the asbestos ceiling. On one occasion, one of his colleagues managed to put the hoist through the asbestos ceiling in the box room in which Mr Weeks was working, causing debris and dust to be released into that room.

On another occasion, Mr Weeks had to help a team of builders who were engaged to demolish an asbestos veranda. Great lumps of debris were smashed to the ground, causing huge clouds of dust. Mr Weeks

had to drive his fork lift into the building under the veranda that was being demolished and collect boxes that were waiting to be taken away. Dust was falling on to him every time he had to gain access to the building this way. It took about a week to demolish the veranda and Mr Weeks was exposed to dust this way every day.

Mr Weeks, a widower, was taken ill in March 2019 with a cough, weight loss and breathlessness. He underwent a diagnostic pleural aspiration which showed mesothelial cells and led to him undergoing a radiological guided biopsy which confirmed epithelioid mesothelioma. He was referred for chemotherapy. Mr Weeks not only received care from his daughters Emily and Victoria but also received considerable help from his neighbours who attended his home each day to help out.

The Defendants would not admit liability and so proceedings were issued and the matter listed for an expedited show cause hearing. Once the date was fixed, the Defendants quickly agreed they were in breach of their duty of care owed and the claim settled for a six figure sum.

Sadly a few only a few weeks after the case was settled, Mr Weeks passed away. Fred's daughters, Emily and Victoria said: "Our Dad was a fiercely independent, kind, proud man, loving dad and granddad, good neighbour and best friend to many.

"He was a wonderful musician who would often play for friends and family.

"He loved nature, he rescued cats, and was well known for feeding the badgers, foxes and birds. If an animal needed help, the neighbours would bring it to Dad who would nurse it to health.

"Dad's illness had a profound impact on his friends and family. We will never forget the strength he showed throughout.

"Like so many, Dad was exposed to asbestos whilst working and providing for his family. Bringing his employers to justice was immensely important for Dad and I would encourage anybody in the same situation to keep fighting for justice. I hope Dad's story will help others in the same situation.

"If it were not for this disease, Dad would be sat in his kitchen with the cats pestering him, telling jokes to friends, spending time with his family and tucking into a warm bowl of cornflakes."

Asbestos in London hospitals: What I've learnt

By Rachel Thomas, Mesothelioma Nurse Advisor at Hugh James

Historically, a mesothelioma diagnosis has been associated with a person's previous asbestos exposure from working in trades to include engineering, carpentry, plumbing, mining, ship building and so on.

However, a recent report has highlighted a worrying trend of healthcare workers and patients being exposed to asbestos in NHS Trust hospitals and buildings.

My current role with Hugh James is as a specialist mesothelioma nurse advisor. I offer support and assistance to our clients who suffer with mesothelioma, and signpost to relevant services. I also support mesothelioma support groups and their members across the country. I endeavour to provide a holistic support service to my clients. My previous role was as a Mesothelioma UK nurse specialist based at Guy's Hospital in London for 12 years. For obvious reasons, I have an interest in the presence of asbestos in our hospitals.

A recent article in the MyLondon newspaper revealed that 451 hospitals and NHS buildings across London contain asbestos. This affects 26 London NHS Trusts. A full list of the Trusts can be found at www.mylondon.news/news/health/451-london-nhs-hospitals-buildings-26034491. For most of the buildings found to contain asbestos, almost all of them are currently accessible to the public.

Many of the buildings were built some years ago and due to their historic significance, the hospital site has remained in these same buildings ever since. For example, Moorfields Eye Hospital has been based in the same building in City Road ever since 1897. Parts of these old buildings are often dilapidated due to their age and asbestos was widely used from the 1930s until the 1980s as a building material for insulation and repair.

With the UK having the highest rate of mesothelioma in the world, it is no surprise that we are seeing links to the disease across many industries. Nevertheless, the one place we should be safe from any harmful substance is our hospitals, whether we are a patient or at work.

The death of Dr Mags Portman, who died of mesothelioma in 2019, prompted a study into the impact of mesothelioma on healthcare professionals. The study, known as the MAGS study, was carried out by Mesothelioma UK and the University of Sheffield.

One key recommendation arising from the study was that awareness of asbestos risk should be added to the mandatory training for new members of NHS staff. The study also pledges to obtain a more accurate picture of the extent of mesothelioma amongst healthcare staff, highlighting that nurses experienced about four to two times higher mesothelioma deaths over the period from 2002-2010.

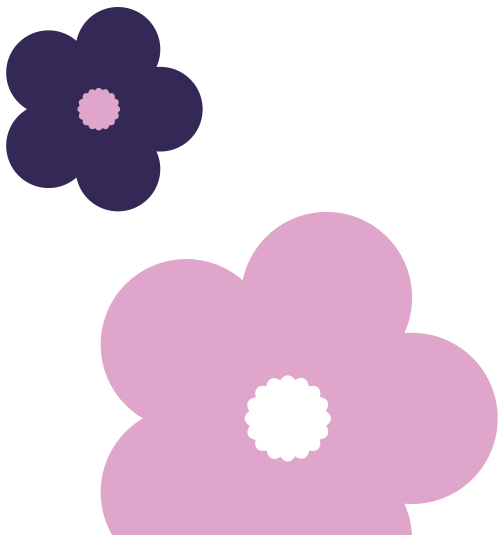
A link to the full study can be found at www.sheffield.ac.uk/murc/news/new-report-mags-study-mesothelioma-healthcare-professionals.

Between 2004 and 2017, there were 691 claims made against the NHS for negligence from asbestos exposure that has resulted in a diagnosis of mesothelioma. In reality, this number is unlikely to represent the total number of healthcare professionals and patients who have been historically exposed to asbestos within NHS premises.

In recent years, we have been instructed in an increasing number of mesothelioma civil compensation claims on behalf of healthcare workers who have developed mesothelioma having been exposed to asbestos in a hospital setting.

My move from a role within the NHS to my role with a law firm has taught me many things. One key learning I have taken away is that mesothelioma is indiscriminate and can affect anyone, even if they have suffered a so called 'low level', fleeting exposure to asbestos.

Sadly the presence of asbestos is not an issue confined to the NHS. Asbestos is present in many of our schools and public buildings as well. Unfortunately it appears that we will continue to see an increasing number of people diagnosed with mesothelioma arising from asbestos exposure in public buildings for a number of years to come.



Appointments

New Clinical Nurse Specialist for Essex

Sam Jayasekara has been appointed as a Mesothelioma UK Clinical Nurse Specialist (CNS) to provide nursing care and support for mesothelioma patients in Essex.

The post is funded by asbestos disease support charity, HASAG. Sam will be based at the Broomfield Hospital in Chelmsford and will also cover Mid and South Essex NHS Foundation Trust's other general hospitals in Basildon and Southend.

As part of the South Cancer Alliance, Sam will link with colleagues across the region to promote equitable access to mesothelioma specific support and treatment throughout the south east.

Sam has been a lung cancer Clinical Nurse Specialist since 2015 and has had a variety of roles both in the acute and community settings. Much of her experience has been based around cancer and palliative care. In the past eight years, Sam has been supporting patients with both mesothelioma and lung cancer.

Sam will bring her expertise and knowledge to strengthen the support available to patients, families and other healthcare professionals.

Commenting on her new role Sam said: "I am excited and honoured to become a Mesothelioma Clinical Nurse Specialist. I hope to become a pivotal link for patients, families and healthcare professionals who have been touched by mesothelioma, providing them with the care and support that they need."

Lynne Squibb, CEO of HASAG, said: "HASAG is thrilled to extend our relationship with Mesothelioma UK and have the opportunity to fund Sam's post as Clinical Nurse Specialist. Our partnership will ensure that those diagnosed with mesothelioma and other asbestos-related diseases throughout Essex will get the best medical care through Sam and the best support through HASAG."

Head of Nursing for Mesothelioma UK, Leah Taylor added: "We are hugely grateful to HASAG for funding Sam's post, enabling us to help more patients and families. We work closely with the team at HASAG and we always appreciate their support. Sam brings a wealth of knowledge and experience to the role, and I know she will be a fantastic addition to the team and be a huge support to those affected by mesothelioma in the Essex region."

Fundraising

Leave a lasting legacy

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, find 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 of the guidance and assurance that you may need.

This service is available on our website for anyone to access at www.mesothelioma.uk.com/leave-a-gift-in-your-will.

SCAN ME

JDR Cable Systems Ltd supports Mesothelioma UK

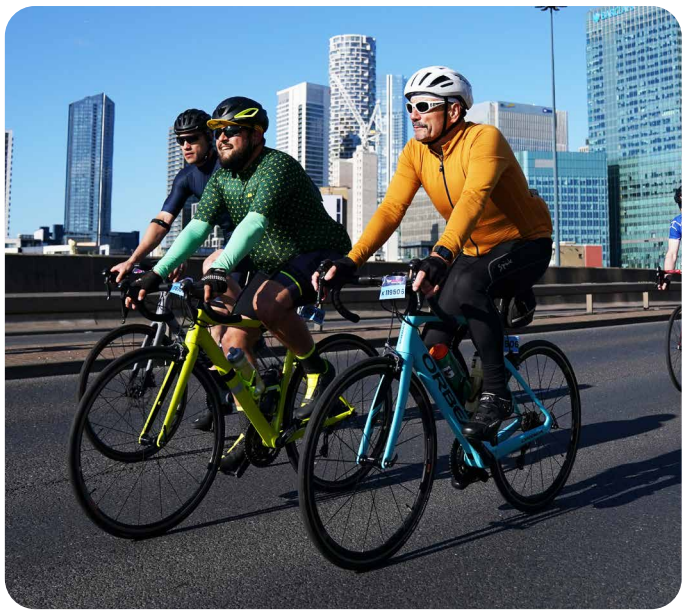
JDR Cable Systems Ltd, a global expert in subsea cables and umbilicals that provide the vital connection to both the renewable energy and oil & gas industry, has announced that its annual charity event will raise funds for Mesothelioma UK and the asbestos support group, Readley.

As part of JDR's commitment to supporting the community, it organises events year on year to raise money in support of their respective local charities. This support for Mesothelioma UK will help to raise awareness of mesothelioma, supporting local specialist nursing units and help local support groups that give the patients and their families a lifeline through counselling and guidance.

JDR welcomes everyone to join them for any of their fundraising events during 2023, especially the 9th Annual Charity Summer Ball which will be held on Friday 26 May 2023 at the Hardwick Hall Hotel, Sedgefield County Durham. The ball includes raffles with fabulous prizes, a three-course meal, live music and a charity auction with some money-can't-buy lots. Last year's event raised over £20,000 for the Mesothelioma UK and Readley.

The price for a table of 10 is £650 or £65 per person. For more information and where to buy tickets visit www.jdrce.co.uk/2023-ball.

Ride London 2022



Calling on cyclists of all abilities! Join #teammeso for this year's RideLondon-Essex 100 and support Mesothelioma UK.

We're looking for fundraisers to participate in a fun and challenging ride to raise money so we can continue supporting our amazing patients and carers.

Sign up now and make a difference while completing a fantastic challenge. Let's ride for a good cause! www.mesothelioma.uk.com/ridelondon-essex-100

Contact fundraising@mesothelioma.uk.com to register your interest for one of our five charity spots.

Kate Coyne

I'm fundraising in memory of my dad who died of mesothelioma back in 2001.

I know first-hand how cruel and frightening it can be for the patient, having looked after my dad in his final days. The disease was less well known all those years ago, therefore it took longer to get a diagnosis and there was little support for families.

The fact that the disease is usually work related from many years ago and is always fatal means that families are dealing with so much all at one time, often with little information or help. Your charity wasn't known to us at the time but I have no doubt the support you provide to patients and their families is priceless in their hour of need.

My training is going well, as is the fundraising.

The marathon is still over three months away so I hope I can keep the momentum up on both fronts until April.

I'm a single mum with two teenage boys so this is no easy feat for me fitting in the training but I think it's a really valuable cause and positive thing to do. My late dad was a quiet man but I know this would make him very proud.

You can read more about Kate's fundraising story at www.justgiving.com/fundraising/Kate-Coyne3.

Daisy and Zoe's run for Mick May

Daisy's dad bravely battled this rare form of cancer for seven years.

In light of the strength, courage and resilience he showed across his battle – together, we wanted to do something to support the amazing charity and celebrate the phenomenal individual that he was!

We believed running a half-marathon was a challenge worth enduring! Both vaguely, athletically capable, we thought we would rise to the challenge. Since we launched the idea, signed up and created the fundraiser, we initially had our target set for £500, but within five hours reached £1,000 and since then have been blown away with the support and generosity of family and friends.

Mesothelioma UK is so grateful to Daisy and Zoe. They have now raised over £4,000!

From cathedrals to kayaks: Albert's mission for Mesothelioma UK

An adventurous Kent-based man is embarking on an incredible series of physical challenges to raise funds to support patients and their families affected by mesothelioma.

To mark his 75th year, Albert Walton will undertake 7.5 gruelling challenges, including a Southwark Cathedral to Canterbury Cathedral walk, Ashford Half Marathon, Yorkshire Dales Three Peaks, Trans Pennine Trail by Tandem, 70km Cycle Time Trial, Triathlon, One Mile Open Water Swim, and a 52-mile kayak around the Isle of Sheppey.

"I'm thrilled to take on these challenges to raise money for such an important cause," says Albert. "As a member of the construction industry, I'm all too aware of the risks of asbestos exposure and the devastating consequences for individuals and families affected by mesothelioma.

"I hope that my efforts will help raise awareness and funds for Mesothelioma UK, as well as encourage others to support this vital charity. Many people in the construction industry are still unaware of the dangers of asbestos. I hope to raise awareness of this critical issue and funds for Mesothelioma UK, which does fantastic work to support those affected by this terrible disease."

To join Albert on any of his challenges or to donate, please visit his JustGiving page at www.justgiving.com/page/albert-walton-1673094432701.

All donations will go directly to Mesothelioma UK to support its work.

Adriana Sutton

Adriana Sutton is seven years old and she held a tombola and raffle stall to raise money for Mesothelioma UK on 26 November 2022.

Adriana chose this charity as her lovely nanny was diagnosed with pleural mesothelioma back in June.

Adriana is also a Brownie which is part of Girl Guiding for 7-10-year-olds, and in raising money for the charity, she has now also gained her charity badge and she raised an amazing £168.93.

Well done, Adriana, you fully deserve your charity badge.

Gemma Moore - RWK Santa in the City

Three members of the RWK Goodman LLP Industrial Disease Team took on the Santa in the City run back in December 2022.

Led by Associate Rachel Hicks, the team ran in memory of all their clients who have courageously battled with mesothelioma, as well as to raise money for the outstanding work that Mesothelioma UK does.

After a glass of warm mulled wine to keep them warm on a very cold evening, the trio donned Santa suits and took to the streets of London with hundreds of other runners.

The team was able to raise £468.75 (inc. Gift Aid) and wanted to send a massive thank you to all who sponsored them.

Callum runs the London Marathon!

So here's a little back story as to why I'm running the London Marathon 2023 for Mesothelioma UK.

On 23 November 2021, I had the shock of my life – a phone call to say my Dad had been diagnosed with an incurable cancer called mesothelioma.

My Dad has always been a fit and healthy man, playing sport all his life and it was only due to a sudden loss of weight, shortness of breath and lack of appetite in the summer of 2021 that he realised something wasn't right.

After many scans and visits to the hospital, our worst nightmare came true. It was from that day I went into survival mode. I needed to do all I can for the man who brought me up in this world. I spent day after day researching this disease I had never heard of, contacting people on the other side of the world who had lived with this cancer for more than 20 years and discovering this small charity called Mesothelioma UK. Having contacted them they gave me and my family some clarity from the news we couldn't get our heads around.

The first year since diagnosis was great, he had a course of chemotherapy and did really well on it with recent scans showing no change or spread of the cancer. He was also playing golf four to five times a week and walking around the four-mile course, but the winter has been tough having really struggled with breathing. The next stage is to get a second line of treatment to hopefully give him more freedom to get out and about again (and get him on the golf course ready for summer).

I thought I would try my luck at getting a ballot spot on the London Marathon as Mesothelioma UK don't get charity spaces due to them being such a small organisation. AND I GOT ONE! So, I'm running for this amazing cause and my incredible Dad!

Thank you for reading my story. This is to beat the disease! Anything you can donate really does mean the world. Thank you.

Sadly Callums' dad passed away on 25 February. We'd like to thank Callum for his unwavering support of the charity. He has already raised over £6,000 and has been continuing to spread awareness of mesothelioma and the dangers of asbestos. Thank you Callum.

If you would like to support Callums' fundraising visit his JustGiving page: www.justgiving.com/fundraising/callum-train.

The Great Manchester Run

We only have six charity places available in the Great Manchester Run! Take part in this half-marathon in the heart of Manchester. In true Mancunian style, it's a party from start to finish, with a high-energy soundtrack, live music, and entertainment zones at every turn!

To register your interest for a spot on #teammeso you can contact our fundraising team on fundraising@mesothelioma.uk.com or on our website www.mesothelioma.uk.com/great-manchester-run.

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.

2023 Events

April

26-28 April
British Thoracic Oncology Group (BTOG) Annual Conference
ICC Belfast
www.btog.org/btog-events/21st-btog-annual-conference-2023

29-30 April
Isle of Wight Challenge
www.ultrachallenge.com/isle-of-wight-challenge

30 April
Glasgow Kiltwalk
www.thekiltwalk.co.uk

May

11-12 May
Lung Cancer Nursing UK (LCNUK) Annual Conference
Birmingham
www.lcnuk.org/annual-conference

June

4 June
Aberdeen Kiltwalk
www.thekiltwalk.co.uk

26-28 June
iMig (international conference of the International Mesothelioma Interest Group)
Lille Grand Palais, France
https://imig2023.org

July

7 July
Action Mesothelioma Day
www.actionmeso.com/GoBlue

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

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