Winter Edition 2020

MESOTHELIOMA UK

MESOTHELIOMA MATTERS

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New Mesothelioma UK Research Centre opens at University of Sheffield

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Launch of monthly Mesothelioma Matters webinars

The first in a regular monthly series of Mesothelioma Matters webinars took place in November when Mesothelioma UK hosted expert speakers discussing 'Nanotubes, Gold and Mesothelioma'.

Researchers from Cambridge and Leeds universities have developed gold nanotubes with physical properties they describe as 'tunable'. This means that they can tailor the wall thickness, microstructure, composition and ability to absorb particular wavelengths of light.

The study, published in the Small journal, has suggested that once inside the cancer cells, the nanotubes – tiny hollow cylinders, one thousandth of the width of a human hair – absorb light, causing them to heat up and thereby killing the mesothelioma cells.

Stephen Evans

Stefan Marciniak

At our Zoom webinar on 30 November 2020, Stephen Evans, Professor of Molecular and Nanoscale Physics, University of Leeds and Stefan Marciniak, Professor of Respiratory Science at the University of Cambridge and Honorary Consultant Respiratory Physician at Addenbrooke's and Papworth Hospitals joined Mesothelioma UK Head of Services, Liz Darlison to share insight into this new breakthrough.

The webinars are free and open to anyone to attend. You can find more details of our monthly webinars at www.mesothelioma.uk.com/events/webinars

NHS Volunteer Responders scheme

The NHS Volunteer Responders scheme continues to accept new referrals and their volunteers are ready to provide vital support to those who meet the criteria.

NHS Volunteer Responders are ready to provide vital support to frontline staff, NHS clinicians and social care professionals. They can be a helping hand for those vulnerable to coronavirus (COVID-19) or any other reason support is needed during the pandemic.

If you'd like to refer someone for the first time, request additional help for someone or to reduce the level of their support, you can make a referral online via the GoodSAM website or call our helpline on 0808 196 3382 (available 8am to 8pm, 7 days per week).
You can see eligibility criteria at www.nhsvolunteerresponders.org.uk/referral

Professor Mick Peake awarded OBE

Professor Michael ('Mick') Peake, British Thoracic Oncology Group (BTOG) Trust board member and chair of the board of Mesothelioma UK, has been awarded an OBE (Order of the British Empire) in Her Majesty The Queen's Birthday 2020 Honours List.

This new national award has been given for the impact that Professor Peake's work has had on improving the care and outcomes of patients with lung cancer and mesothelioma in the UK, and his contribution to the development of the National Cancer Registration and Analysis Service.

Professor Peake was a Consultant Respiratory (Chest) Physician in the UHL trust, based at the Glenfield Hospital, from 2000 to 2017. He retains an Emeritus Consultant position there and in 2016, the University of Leicester awarded him an Honorary Chair in Respiratory Medicine in recognition of the impact of his published and policy work in the fields of lung cancer and mesothelioma.

He established the National Lung Cancer Audit which has been running since 2004, was National Lead Clinician for Lung Cancer for 12 years in a previous iteration of NHS Improvement, and was a co-founder of the National Cancer Intelligence Network which has since become the National Cancer Registration and Analysis Service, where he was the National Clinical Lead. He was Clinical Head of the thoracic oncology unit at Glenfield Hospital when it won 'Oncology Team of the of the Year' award in the National Health & Social Care Awards in 2002.

He was a Founder of the UK Lung Cancer Coalition and in partial retirement, currently works as the Clinical Director of the Centre for Cancer Outcomes, hosted by University College London Hospitals. He has published nearly 140 peer reviewed papers and lectured widely across the UK and internationally.

The Burdett Trust for Nursing awards grant to Mesothelioma UK

Independent charitable trust, The Burdett Trust for Nursing has donated a £10,000 grant to Mesothelioma UK. The funding has enabled the charity to appoint a Project Lead to establish an All Wales Mesothelioma Multi-Disciplinary Team (MDT) and support the delivery of clinical nurse specialist care to patients across Wales (see article on page 12).

The Burdett Trust for Nursing is named after Sir Henry Burdett KCB, the founder of the Royal National Pension Fund for Nurses (RNPFN). The Trust makes grants in support of nurse-led projects, using its funds to empower nurses and make significant improvements to the patient care environment.

Shirley Banes, Chief Executive at the Burdett Trust said: "The Burdett Trust is proud to be able to support Mesothelioma UK with a grant of £10,000 towards providing an enhanced service for patients and families in Wales. The integrated work they do on the frontline alongside the NHS, via their specialist nurses is vital. Our Trust recognises the importance of providing grants to charities that carry out essential support services such as Mesothelioma UK."

Lorraine Creech, Head of Nursing for Mesothelioma UK added: "We're extremely grateful for the grant of £10,000 from The Burdett Trust. Grants like this are vital to us as we rely entirely on donations and fundraisers to fund the running of the charity. This funding will help us to establish a better provision of specialist support and expertise for patients in Wales where there is currently no specialist multi-disciplinary team meeting for all of the country. The project in Wales will help to us to achieve our aim of ensuring equitable access to first-class treatment and care for all patients in the UK."

Preventing asbestos exposures during Covid

Covid means many UK buildings have reduced levels of on-site management or are partially occupied or vacant, which makes it harder for dutyholders and estates teams to manage their asbestos and contractors safely.

UKNAR CIC's Asbestos SMART QR code technology can help by making the latest asbestos registers accessible to all on site that need to see them – 24/7 – simply by scanning a QR code with their mobile phone! No management needs to be present.

Since UKNAR started in January 2020, Asbestos SMART has been adopted in over 200 workplaces and schools, better safeguarding thousands of employees and students.

Dutyholders, contractors and staff save time, hassle and money – not just lives. Regular reports can provide evidence and reassurance that this potentially deadly risk is being managed effectively under challenging circumstances.

Dutyholders only need to supply a PDF of their latest asbestos register to UKNAR who will check that it complies with basic HSE requirements before converting it into a digital format, easily legible on a mobile phone. A unique QR code is assigned that will be incorporated into an appropriate signage template. Costs are as little as £195 per register, dependent on size. The risks and costs of asbestos disturbance by under-informed contractors can be reduced significantly with just one hour of a dutyholder's time.

Every school and university that signs up to UKNAR's Asbestos SMART technology will benefit from a free early adopter trial programme.

Five per cent of Asbestos SMART's licence fees go to Mesothelioma UK as our charity partners.

To register a school, university or workplace, please contact stuart.towers@uknar.org. For further information, visit www.uknar.org

Virtual Patient and Carer Day 2020

Friday 2 October 2020 saw us host our 15th annual Patient and Carer Day. This year, due to COVID-19, we did it 'virtually' and were joined by almost 200 viewers. It was a day of learning and sharing with others with similar experiences.

We're grateful to the speakers who talked about the latest on mesothelioma clinical trials, treatments and research including Respublica's Airtight On Asbestos project.

We were also lucky enough to be joined by Paul Cook, who talked about his mesothelioma journey and his plans for his charity, Erase Meso. Our nurses enjoyed hosting 'virtual' lunch breakout rooms which specifically discussed carers, peritoneal mesothelioma and thoracic surgery.

The video recordings of the event are available to watch on our YouTube channel – search for Mesothelioma UK on www.youtube.com

Thank you to everyone who tuned in. It was different, but hopefully just as informative.

Newly published research in mesothelioma

Compiled by the University Hospitals of Leicester Clinical Librarian Services

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

New scientific research

Association of tumour mutational burden with outcomes in patients with advanced solid tumours treated with pembrolizumab: prospective biomarker analysis of the multicohort, open-label, phase 2 KEYNOTE-158 study.
Author(s): Marabelle, Aurélien; Fakih, Marwan; Lopez, Juanita; Shah, Manisha; Shapira-Frommer, Ronnie et al.
Source: The Lancet. Oncology; Oct 2020; vol. 21 (no. 10); p. 1353-1365

Durvalumab with first-line chemotherapy in previously untreated malignant pleural mesothelioma (DREAM): a multicentre, single-arm, phase 2 trial with a safety run-in.
Author(s): Nowak, Anna K; Lesterhuis, W Joost; Kok, Peey-Sei; Brown, Chris; Hughes, Brett Gm et al.
Source: The Lancet. Oncology; Sep 2020; vol. 21 (no. 9); p. 1213-1223

Phase 1 study of the immunotoxin LMB-100 in patients with mesothelioma and other solid tumors expressing mesothelin.
Author(s): Hassan, Raffit; Alewine, Christine; Mian, Idrees; Spreafico, Anna; Siu, Lillian L et al.
Source: Cancer; Nov 2020; vol. 126 (no. 22); p. 4936-4947

Patient-derived malignant pleural mesothelioma cell cultures: a tool to advance biomarker-driven treatments.
Author(s): Kanellakis, Nikolaos I; Asciak, Rachelle; Hamid, Megat Abd; Yao, Xuan; McCole, Mark et al.
Source: Thorax; Nov 2020; vol. 75 (no. 11); p. 1004-1008

Malignant Pleural Mesothelioma: State of the Art
Author(s): Various
Source: Thoracic Surgery Clinics: Volume 30, Issue 4. November 2020 (Special Issue on MPM)

Clinical Features in Patients With Malignant Pleural Mesothelioma With 5-Year Survival and Evaluation of Original Diagnoses.
Author(s): Paajanen, Juuso; Laaksonen, Sanna; Ilonen, Ilkka; Vehmas, Tapio; Mäyränpää, Mikko I et al.
Source: Clinical lung cancer; Nov 2020; vol. 21 (no. 6); p. e633

Randomized Study of Maintenance Pemetrexed Versus Observation for Treatment of Malignant Pleural Mesothelioma: CALGB 30901.
Author(s): Dudek, Arkadiusz Z; Wang, Xiaofei; Gu, Lin; Duong, Stephanie; Stinchcombe, Thomas E et al.
Source: Clinical lung cancer; Nov 2020; vol. 21 (no. 6); p. 553

Qualitative studies and patient experience

CANcer BEhavioural nutrition and exercise feasibility trial (CanBenefit); phase I qualitative interview findings.
Author(s): Swan, Flavia; Chen, Hong; Forbes, Cynthia C; Johnson, Miriam J; Lind, Michael
Source Journal of geriatric oncology; Oct 2020

Gender-based Disparities in Receipt of Care and Survival in Malignant Pleural Mesothelioma.
Author(s): Barsky, Andrew R; Ahern, Christopher A; Venigalla, Sriram; Verma, Vivek; Anstadt, Emily J et al.
Source: Clinical lung cancer; Nov 2020; vol. 21 (no. 6); p. e583

What are the psychological effects of mesothelioma on patients and their carers? A scoping review.
Author(s): Sherborne ; Seymour, Jane; Taylor, Bethany; Tod, Angela
Source: Psycho-Oncology; Oct 2020; vol. 29 (no. 10); p. 1464-1473

Predictors of filing claims and receiving compensation in malignant mesothelioma patients.
Author(s): Marinaccio ; Gariazzo, Claudio; Di Marzio, Davide; Iavicoli, Sergio
Source: Health Policy; Sep 2020; vol. 124 (no. 9); p. 1032-1040

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

UHL Clinical Librarian Service
"bringing you the evidence"

Public Advisory Board

Mesothelioma UK has reorganised its Public Advisory Board (PAB) which aims to provide the insight of mesothelioma stakeholders to support the planning and development of the charity's services. The PAB is the voice of the mesothelioma community and a bridge between the charity and patients. It makes recommendations and drives the agenda regarding research, awareness, information and patient support.

The Board consists of:

- A chair – a link between the PAB and the Board of Trustees.
- A maximum of 16 patients and carers
- A maximum of 3 representatives of other charities
- A maximum of 3 representatives from Mesothelioma UK

There are four main sub-groups on the advisory board:

Patient Support Committee
The Patient Support Committee has specific responsibility for advising on direct support activities, including nursing services, benefits advisors and patient travel support.

Research and Audit Committee
The Research and Audit Committee has specific responsibility for advising the Board of Trustees, the management team and the Scientific Committee.

Information Committee
The Information Committee has specific responsibility for advising the Board and management team.

Awareness Committee
The Awareness Committee has specific responsibility to advise the Board and the management team.

Public Advisory Board members

Jeremy Steele
Medical professional and Chair of the PAB

John Edwards
Medical professional

Dave Staley	Mesothelioma patient
Mavis Nye	Mesothelioma patient
Simon Clark	Mesothelioma patient
Carrie Twist	Mesothelioma patient (peritoneal)
Lorraine Creech	Mesothelioma UK representative
Faye Forde	Mesothelioma UK representative
Julie Morton	Mesothelioma UK representative and secretary of the PAB
Ravi Ruparelia	Relative/carer of former mesothelioma patient
Claire Davidson	Relative/carer of former mesothelioma patient
Ana Fuller	Relative/carer of former mesothelioma patient
Maureen Cook	Relative/carer of former mesothelioma patient
Joanne Tatum	Relative/carer of former mesothelioma patient
Tracey Wood	Relative/carer of former mesothelioma patient
Phyllis Craig	Representative from other charity
Lynne Squibb	Representative from other charity

DWP confirms change to six-month rule for terminally ill benefit claimants

Department for Work & Pensions

Following a review of the rule that states terminally ill patients must have six months or less to live to 'fast track' their claim to certain benefits, the Department of Work and Pensions is now 'working at great speed' to bring forward much-needed changes to the six-month rule.

DWP Minister for Disabled People, Health and Work, Justin Tomlinson has confirmed that the six-month rule for terminally ill benefit claimants is to be changed once the government's review of special rules for the terminally ill has been completed.

To access the 'fast track' benefits, a medical professional must complete a DS1500 form stating that death would be 'not unexpected' within six months. In practice, this can prove tricky for certain illnesses including mesothelioma, which although always terminal, does not necessarily result in death within six months of diagnosis.

Mesothelioma UK is pleased that a review is taking place as the six-month rule does not accurately reflect the way people with terminal illnesses such as mesothelioma live today. There are no details about what the changes will be but we will be keeping abreast of the situation and will share updates as and when there are any.

If you have any questions about benefit claims, please call our information line on 0800 169 2409 and we can put you in touch with one of our dedicated benefits advisors.

Do It For Yourself

Mesothelioma UK is proudly supporting the Do It For Yourself campaign as part of a coalition which aims to raise awareness of the signs of lung cancer and encourage people to contact their GP if they've been experiencing a cough or ongoing breathlessness for three weeks or more.

This year, we've become a nation of DIYers, spending time looking after our home but one in three of us delayed looking after ourselves. Lung cancer is the third most common cancer in the UK

but lung cancer referrals have dropped this year in some areas.

Not every cough is a COVID Cough; having a cough for three weeks or more or getting out of breath doing things you used to be able to do could be signs of lung cancer. At Mesothelioma UK, we know that the earlier cancer is diagnosed, the more treatment options are available.

If you have been impacted by lung cancer and want to share your story to help spread the message, then please get in touch. And, if you're experiencing symptoms, contact your GP and 'Do it For Yourself'.

Patient Care Passports

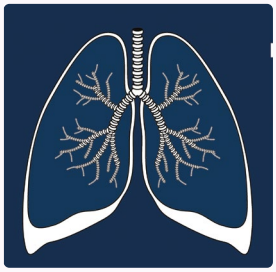
The planned care that you receive following a diagnosis can mean that there's a lot of information, dates, medical information and contact details to remember. Our 'My Mesothelioma Care Passport' is the ideal resource to help with this. It's a pack designed to help patients stay up-to-date with the planned care that they have discussed and agreed with their healthcare professionals.

The passport is a concise record of your care to date, helping you to understand and discuss it with anyone you choose. It can be used to store contact details, appointment times/dates, x-ray and scan reports, clinical letters, prescriptions and anything else related to your care.

The passports are available from healthcare professionals and can also be downloaded from our website. For our Welsh-speaking patients, the passport is being translated into Welsh and it will also be included in the information packs given to patients in Scotland.

Airtight on Asbestos

The Airtight on Asbestos (airtightonasbestos.uk) campaign has been running since July 2019. The purpose is to raise awareness of the current failings in the health & safety regime, regarding the management of asbestos in buildings, and to bring UK policy and practice in line with the evidence and the best international standards. It aims to get upstream of the problem and put in place a preventative strategy that can limit unnecessary exposure to asbestos, and stop so many people dying from asbestos-related disease in the future.



The campaign has recently completed the final episode of a four-part audio documentary series – Dust to Dust (airtightonasbestos.uk/podcast). In this, the history of asbestos is charted from its early use to the discovery of its dangers and harm. Part IV – Unmasking the Hidden Killer - outlines the flaws in the UK's approach to the management of asbestos in our built environment and the failures of accountability. It summarises the main findings of the campaign to date and recommendations for workable alternatives to the Health and Safety Executive's (HSE's) current practice.

As we move into 2021, the campaign will focus on debunking the Government's position and the advice that they are receiving from HSE. Airtight on Asbestos will be looking to work in partnership with all organisations seeking to improve how asbestos is currently managed, so that the most high-risk buildings are identified and asbestos removed as part of a phased programme.

APPOINTMENTS

New clinical nurse specialist for patients in West and North Yorkshire

Simon Bolton has been appointed as a new Clinical Nurse Specialist at Calderdale and Huddersfield NHS Foundation Trust to provide advice, care and support, improving access to treatment for mesothelioma patients across North and West Yorkshire.

The new full-time role is funded by Mesothelioma UK with support from legal firms including The Asbestos Law Partnership, Irwin Mitchell, Leigh Day, Slater and Gordon, and Thompsons. In his new role, Simon will be responsible for liaising with multi-disciplinary teams across seven Yorkshire hospitals, focusing on increasing information and access to clinical trials across the UK, and co-ordinating the MESothelioma Support Yorkshire (MESSY) group for mesothelioma patients and carers.

Previously, Simon has worked as a Mesothelioma Clinical Nurse Specialist at Harrogate District Hospital and has also worked for the Harrogate and District NHS Foundation Trust as a lung cancer nurse specialist for over nine years.

Commenting on his new role, Simon Bolton said: "It's fantastic to be back in the Mesothelioma UK team, raising awareness of the disease, and supporting patients and their families throughout their treatment and care journey."

New Clinical Nurse Specialist for Essex

Angela Goldfinch has been appointed as a new Mesothelioma UK Clinical Nurse Specialist for the Mid and South Essex NHS Foundation Trust.

The Clinical Nurse Specialist position is funded by Mesothelioma UK and HASAG, a leading UK support group for people living with mesothelioma and asbestos diseases in London and the south east.

In her new role, Angela will focus on caring for patients with lung cancer and 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, and also healthcare professionals.

Angela qualified as Registered Nurse in 2004 and has worked in respiratory medicine, oncology and palliative care throughout her career. In 2013 she took up a position as Lung Cancer Nurse at Basildon Hospital and was a key worker for patients diagnosed with both lung cancer and mesothelioma, offering them hospital-based support from pre-diagnosis through to treatment and palliative care.

Commenting on her new role, Angela said: "Since working as a Clinical Nurse Specialist I have always been inspired by the Mesothelioma UK nurses and to now have the opportunity to join them is such an honour.

"I am really looking forward to becoming a keyworker to patients and families locally and providing a specialist support role in Essex. This will include using education to promote awareness and setting up a support group alongside HASAG."

Welcoming new recruits to our Operations Team!

Mesothelioma UK has recently strengthened its Operations Team with the recruitment of two new roles, both based at its Leicester HQ.

Samantha Morgan joins as a Senior Project Manager, responsible for overseeing the charity's research audit work and engaging with the new Research Centre in Sheffield (see the article on pages 22-23 in this edition for more on this). Samantha will be focused on the funded research projects and disseminating and communicating the information gained from these studies with Mesothelioma UK's stakeholders and policymakers.

Samantha's background is in project and quality management in the local NHS, looking at patient safety, service re-design and more, working with consultants and GPs.

Hazel Curtis is Mesothelioma UK's new Finance Assistant, working with the charity's Finance Manager on banking checks and the Donorfy payment system. Hazel brings expertise in revenue and capital, budget setting, year-end monitoring, treasury management and insurance, following 24 years' experience in local government finance with various local authorities in Leicestershire.

New Trustees appointed

Mesothelioma UK has recently added two new key appointments to our terrific team of Trustees:

Melanie Waters was appointed Chief Executive Officer of Help for Heroes in November 2016, taking over from co-founders, Bryn and Emma Parry, who established the Charity in 2007. Prior to joining Help for Heroes Melanie was Chief Executive of The Poppy Factory – an independent employment charity, which puts the recovery and employment of disabled ex-Service people and their families at its heart.

Nick Maskell is a Professor of Respiratory Medicine at University of Bristol (UoB) and Honorary Consultant Chest Physician at North Bristol NHS Trust. He was appointed as a consultant there in 2004. He leads the pleural service at Southmead hospital and is the head of the Academic Respiratory Unit at UoB.

He has a major interest in mesothelioma, running a tertiary mesothelioma clinic and chairing the weekly regional mesothelioma MDT. He chaired the current BTS mesothelioma guideline group and was on the committee for the ERS mesothelioma guidelines. He is also a co-chair of the forthcoming BTS pleural disease guidelines (2021) and is an advised to the NPSA on pleural safety matters related to pleural interventions.

New Mesothelioma UK Team Leader appointed in Scotland

Mesothelioma UK has appointed Carolyn MacRae as its new Team Leader for Scotland. Carolyn is a Mesothelioma UK Clinical Nurse Specialist (CNS), based at NHS Greater Glasgow and Clyde health board. She will manage an expanding specialist nursing team of six across Scotland and will join two other Mesothelioma UK Team Leaders who cover other parts of the UK.

This new Team Leader post is funded by Mesothelioma UK and local support group, Action on Asbestos. Carolyn will support patients across the region during their diagnosis and treatment, answer calls to the Mesothelioma UK information line, advise on clinical trials, and provide palliative and end of life care and support.

Carolyn qualified in 2000 and was appointed as a Mesothelioma UK Clinical Nurse Specialist in 2017. Prior to her role with Mesothelioma UK she worked for over 10 years as a Respiratory CNS in south Glasgow, predominantly with patients with chronic obstructive pulmonary disease (COPD), interstitial lung disease and asthma, and has experience in the acute, community, educational and outpatient settings.

Commenting on her new role, Carolyn said: "I'm delighted to be taking on this new role, funded by Mesothelioma UK and Action on Asbestos. Clinical Nurse Specialists have the potential to transform care for those affected by mesothelioma by offering a dedicated resource for patients and their loved ones.

"The Macmillan Scottish Mesothelioma Network provides patients with high quality care and information, and ensures equity of access to treatment and clinical trials. The Network has huge potential as a force for change in mesothelioma-related practice and outcomes, and it is an honour to be a part of it as it continues to develop and grow.

"Hopefully together, we can support more patients throughout their journey and help to champion research into better treatments, practice and ultimately, better outcomes."

Lorraine Creech, Mesothelioma UK Head of Nursing, added: "Mesothelioma UK is proud to welcome Carolyn as our first Team Leader for Scotland. Our partnership working with the Macmillan Scottish Mesothelioma Network has been the springboard for this role and we now have five Mesothelioma UK Clinical Nurse Specialists and one Pleural Specialist Nurse in an affiliated role throughout Scotland. We also have a further post in the planning stage.

"This hub and spoke set up mirrors Mesothelioma UK in England and as the number of Mesothelioma UK Clinical Nurse Specialists increases in Scotland, local leadership is vital. Carolyn has a wealth of experience in her current role and has already demonstrated her leadership skills and drive to make mesothelioma matter in Scotland."

Director and senior WRO of Action on Asbestos (formerly Clydeside action on asbestos) Phyllis Craig MBE stated: "Our charity is delighted that Carolyn has now been appointed as team leader for Scotland's Mesothelioma UK nurses. We were delighted that we have been able to part fund this post and hope to work in partnership with Mesothelioma UK to fund additional nursing posts in Scotland in the future."

Nurses update

Mesothelioma UK is delighted that our team of Clinical Nurse Specialists is going from strength to strength and we're getting closer to our target of placing nurses in every Cancer Alliance region in the country. We now have a total of 29 nurses including three team leaders. Our recently appointed nurses are based in Sunderland, Cambridge, Morecambe Bay and Glasgow.

Joanne Anderson has been appointed as Clinical Nurse Specialist at South Tyneside and Sunderland NHS Foundation Trust and is based at Sunderland Royal Hospital. She also supports mesothelioma patients at South Tyneside District Hospital.

Joanne Songco is a Lung Cancer Specialist Nurse in the Thoracic Oncology Dept at Royal Papworth Hospital, Cambridge where she has worked since 1996.

Joanne Fisher is a Lung Cancer Nurse Specialist with Morecambe Bay NHS Trust, predominantly based at Furness General Hospital in Furness.

Laura McNaughton is based at Queen Elizabeth University Hospital and supports patients in the west of Scotland.

New research internship

The Mesothelioma UK Operations Team welcomes De Montfort University student, Jakub Sticky as he begins his internship with the charity. Jakub is studying for an MSc in Psychological Wellbeing.

Jakub has worked with the team for 30 hours during November and will potentially join us again for 30-40 hours after Christmas. Supporting Sam Morgan, Senior Projects Officer, Jakub will be working on developing and logging the impact of the MAGS report which examined the risks of asbestos exposure, and hence mesothelioma, to healthcare professionals.

New project to support asbestos cancer patients in Wales

A new project has been launched to support patients in Wales, funded by Mesothelioma UK, with support from the Burdett Trust for Nursing. Mesothelioma UK Clinical Nurse Specialist for Wales, Sarah Morgan will lead on the project to review patient needs across Wales, working towards establishing a coordinated All-Wales specialist mesothelioma service. Sarah's post is hosted by the Hywel Dda Health Board.

The project will likely establish a system using a hub and spoke approach so that all patients in Wales, diagnosed with mesothelioma, are supported by a specialist mesothelioma nurse, are registered at a specialist mesothelioma multi-disciplinary team meeting and have access to the best treatment, care and clinical trials available.

Mesothelioma UK will look to establish a Welsh network of specialist nurses to complement and support the work of existing the Clinical Nurse Specialist, to ensure support for more patients and increase knowledge of mesothelioma among healthcare professionals in Wales.

Patients in Wales often experience difficulties accessing specialist centres because of limited transport links and the rural nature of Wales. Access to clinical trials is also more difficult for patients in Wales so this enhancement of services is vital.

Sarah will lead the project and she has already secured the support from patients and the wider mesothelioma community in Wales including clinicians.

Sarah Morgan

Commenting on the project, Sarah said: "I am delighted to be leading this project and I look forward to working closely with my colleagues throughout Wales to improve services for all those affected by mesothelioma. Many cancer patients and cancer services have been badly affected by the recent pandemic and none more so than mesothelioma patients and services. The need for an All Wales approach to specialist services for mesothelioma has never been more urgent."

Lorraine Creech, Mesothelioma UK Head of Nursing, added: "We are grateful for the support of the Burdett Trust for Nursing to get this project up and running. The project will run for two years and as Sarah is currently the only Mesothelioma UK Clinical Nurse Specialist in Wales, she has a wealth of experience about healthcare in Wales as a devolved administration and also about the needs of people with mesothelioma. Sarah continually works with Mesothelioma UK to ensure we consider how our support and advice services address the specific needs of people with mesothelioma in Wales."

PATIENT STORIES

Simon Lawrence, 60, was diagnosed with mesothelioma in March 2017 and given just three weeks to live. Three years later, he is still here and writing a self-help book, Dare To Live.

Simon, a photojournalist and cinematographer from Hampshire, has always believed in the power of the mind and is certain that the mind is stronger than the body. During his career, he has written countless articles about how positive thinking can help people tackle many problems. And so, when he was diagnosed, one of his first thoughts was "Good, I can write a book about this."

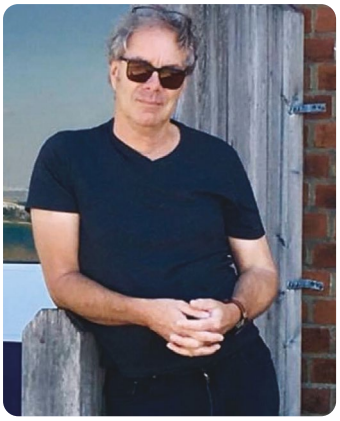
Unusually, Simon says that he did not feel frightened when the consultant gave him his diagnosis. He saw it as a challenge, an opportunity to prove what he had been writing about for years - that the mind is more powerful than the body.

Even as he was on his way home from the hospital, he came up with the title for the book he was going to write – Dare To Live. Simon was determined not to simply accept his three-week prognosis and feel helpless; he knew that he had a choice to do something.

It was in 2016 when Simon first noticed that he was feeling unwell and slightly breathless. He put it down to pollution in the atmosphere in London, where he was working. He wasn't overly concerned though and was still able to cycle several times per week.

A few months later, he woke with a pain in his shoulder. He thought that he had just slept awkwardly on it. Simon admits that he felt that he was getting a bit slower at things but at 57, simply put it down to getting older.

It wasn't until January 2017 that he eventually sought medical help after he experienced some visual disturbances.



A friend feared that he may be having a stroke and called an ambulance. At the hospital, Simon was told he had had optical migraines and was sent home.

When his vision was affected again a month later, Simon visited his GP. As a non-smoker, Simon wasn't a priority for a CT scan but was booked in when Simon mentioned that he had been exposed to asbestos in the past (in his 20s, he had photographed factories containing asbestos).

Simon was sent for a CT scan a few days later and three days after that was given a diagnosis of sarcomatoid mesothelioma and told to put his affairs in order as it was likely that he only had three weeks to live. It transpired that he also had a tumour pressing on his jugular vein which was what had caused the problems with his vision.

Following the diagnosis, Simon immediately took action and began researching things he could do to beat his prognosis. Two months later, a healthier diet - organic, no sugar, alcohol or caffeine – and exercise, combined with a positive mind-set saw Simon feeling much stronger.

In June 2017, he was offered chemotherapy and had six rounds over an 18-week period and 13 rounds of radiotherapy. After the third chemo treatment, there was a reduction in the tumour which did surprise everybody. Since then, Simon's been in stable, partial remission stage and his outlook has remained positive. He has had no further treatment, apart from regular scans.

Simon said: "What I want to do with my book is show people that you can get through this. You don't have to give away all your power to a medical person who tells you that you are going to die.

"You can fight back. I did and I'm here at 60, believing I can get through this and enjoying every moment of my life."

LEGAL PANEL

Why are they asking me all of these questions?

By Jon Andrews, Principal Lawyer and Team Leader, Industrial Disease, Slater and Gordon

The practicalities of overcoming technical defences in damages claims.

When I was asked to contribute this article, I thought long and hard about what I might helpfully say. The case law in relation to mesothelioma claims, and in particular with regard to the central issue of establishing liability, continues to develop at a pace. It was therefore tempting to provide a detailed technical update on those important issues but on reflection, I thought it was more helpful just to take a step back and try to give some insight into the practical side of the arguments that we face in our claims day to day.

As a lawyer, it is all too tempting to become immersed in complex and technical arguments, which important as they are, can seem needlessly complex and possibly irrelevant to our clients and other professionals we work with. I think it is always important to think about the advice you give, and to make it relevant and understandable. I hope to apply that logic to what follows!

The reality is that legal arguments in mesothelioma claims show no signs of becoming any less technical or challenging than they have been for several years now. In particular, a legal debate rages around the issue of what level of asbestos exposure might foreseeably pose a risk of mesothelioma developing in later life, and it can be a difficult job to translate those complex arguments into practical legal advice. However, it is important to do just that.

Quite often, and I have to say not unreasonably, clients feel that their diagnosis, properly accompanied by advice that the disease is a result of asbestos exposure, should by itself enable compensation to be successfully claimed. Of course, as far as state benefits are concerned, that is largely correct.

Jon Andrews

However, the damages available by means of bringing a civil claim, that is a claim through the courts, normally against former employers, are almost inevitably far more substantial. Nowadays, particularly given the welcome developments regarding immunotherapy treatment, it is all the more important to pursue civil claims and seek damages which may fund treatment and which go far more towards meeting financial and other losses. It is in relation to those civil claims, that the arguments can be very challenging.

I first acted for a client suffering from mesothelioma over 25 years ago. Claims at that time tended to be made by people with clear histories of exposure. Working in and around Manchester, I would quite frequently act for dockers who had unloaded hessian sacks of asbestos at Manchester docks. They were equipped with a metal hook to enable them to move the bags around, which would of course damage the bags and release clouds of asbestos.

There are other similar examples of obvious exposure to be found in different geographical areas and different walks of life. The common theme however was that the amount of asbestos involved could leave no reasonable person questioning whether at least the risk of mesothelioma developing in later life had been increased.

Increasingly, the clients we see have far less obvious sources of asbestos exposure than the Manchester dockers I used to act for. Normally, it is still possible to identify where and when the exposure will have occurred, but the amounts of asbestos involved can frequently be far less, and it is in this territory that the insurance industry has chosen to fight some recent battles.

The pendulum has swung both ways. In the well reported case of Bussey, an outcome was achieved which should give encouragement to Claimants. The claim was initially dismissed by the court because it was said asbestos exposure, which undoubtedly had occurred between 1965 and 1968, and which it was accepted had caused mesothelioma to develop, did not exceed guidance levels issued in a government document called TDN 13.

That finding was appealed, and effectively overturned, with the case being referred back to the original court to reconsider. The claim was then successfully resolved.

This made it clear that whilst guidelines in force at the time of exposure must be considered, they do not provide the Defendant with anything approaching a cast iron defence.

In the more recent case of Bannister, the Defendant adopted a different line of attack, relying on a statistical approach as to whether low or modest asbestos exposure increases the risk of mesothelioma. The argument being that if it does not statistically increase the risk and if a doctor at that time may have reassured someone that they did not face a risk of the disease, then liability cannot be established against the Defendant. That analysis was accepted by the court on that occasion and the claim was dismissed.

In my view, this is open to challenge and it is an argument that can be overcome, but only with very carefully assembled and considered evidence.

I have not tried here to analyse these cases in any detail, and there are numerous articles available online from both a Claimant and Defendant perspective which will provide all the background information you could possibly require.

The point I am making is that when we are trying to give practical advice, we do so against a background of evermore technical and complex attempts being made to resist liability.

The good news is that mesothelioma claims are still of course being successfully concluded, proper damages are being paid and perhaps most importantly of all, treatment is being funded. More than ever, this does depend upon very careful assembling of evidence, and detail about the circumstances of exposure.

In particular, we will always be asking about the duration of exposure, the likely amounts of asbestos involved, the colour of the asbestos and those practical day to day details as to how exposure occurred. We do appreciate that sometimes the answers to these questions must seem obvious, but they really can make the difference between a successful claim and one that fails.

It is also the case that the expert witnesses we work with, and we do pride ourselves on always seeking to work with the very best, are entirely conversant with these arguments and well equipped to address them. Likewise, the barristers we work with must be familiar with these arguments and able to resist them wherever possible.

It is likely that technical arguments will continue to be raised and so our preparation for cases will have to grow evermore detailed. It is my belief that gradually Bannister will be shown to have limited relevance and should not serve to prevent good, if perhaps difficult, claims from succeeding.

So, running a claim is not as straightforward as we wish it would be, but I am pleased to say claims are very much still being successfully concluded despite these challenges. However, the foundations we need to overcome these technical challenges do result in us asking an awful lot of searching questions and I hope this begins to explain why.

Food for thought - asbestos in the food industry

By Natalia Rushworth-White and Mary Mulhall, specialist mesothelioma solicitors at Hugh James

Natalia Rushworth-White

Mary Mulhall

Asbestos exposure and the food industry may seem like an unusual mix. After all, food production tends nowadays to be associated with a clean and hygienic environment. This was not always the case however, as demonstrated by a string of recent legal claims brought by Hugh James in which the legacy of asbestos usage within the food industry has come to the fore.

There are of course a number of stages which food goes to, from being a crop grown in a field or an animal reared on a farm, to the meals which end up on our plates. Along the way, food might be prepared or processed in a factory, sold to us in a store or cooked for us by chefs in restaurants and cafeterias. It is becoming increasingly clear that none of these areas are immune from the hazards presented by asbestos usage within this country.

Asbestos has long been used in agricultural settings as a building material. Famed for its fire-resistant properties, asbestos was widely installed in barns, stables, chicken coops and animal sheds.

Over time and exposure to the elements, the asbestos becomes damaged and disturbed, exposing farm workers to harmful levels of asbestos dust and fibres which are released from the material as it deteriorates.

Asbestos was commonly used too within industrial kitchens and food production factories where powdered lagging was used to insulate the steam pipes which powered the ovens and production lines. Given the long latency period between exposure to asbestos dust and the development of illness, many of our clients are only now experiencing the effects of exposure to asbestos within their working places during the 1960s and 1970s.

For instance, Hugh James is acting on behalf of the family of a gentleman named Mr C who died of mesothelioma last Christmas. He had been exposed to asbestos dust whilst working in the industrial kitchen of a large chain of tea shops during the 1960s, making puddings and soups to sell to customers. The pipes had been insulated with asbestos lagging and Mr C recalled these being damaged as a result of routine repair and maintenance work, releasing asbestos dust into the air around him.

Another client, Des, had worked in a biscuit factory during the mid-1960s and had been exposed to asbestos dust released during routine repair works to the production line machinery, which was steam-powered. Although nowadays such environments would be subject to strict health and safety protocols, back in the 1950s and 1960s, working conditions were very different and neither Mr C nor Des were warned of the dangers of asbestos exposure nor provided with any personal protective equipment.

Asbestos products were also widely used in retail store and restaurants, satisfying building regulations by providing fire proofing throughout the stores from floor to ceiling. Shoppers and workers moved around these spaces, unknowingly surrounded by asbestos materials which they accidentally knocked into with their trolleys and baskets, releasing deadly fibres into the atmosphere. These areas included the food halls of Marks and Spencer stores.

In the late 1960s, Mrs Inman worked in one such food hall. She had started as a 16 year old working for the reputable retailer and she remembered well the high standards that employees were held to account to for cleanliness and customer service to uphold Marks and Spencer's strong brand image.

Standards were not always the same for staff when behind closed doors, however, and refurbishment works undertaken in the food hall where Mrs Inman worked involved drilling into asbestos ceiling tiles, releasing fibres into the air and onto the covered food. This went on for many weeks and Mrs Inman was required to sweep up the asbestos dust and debris out of hours, to ensure the food hall was spotless for the customers' arrival. Mrs Inman sadly went on to develop mesothelioma.

Hugh James acted for Mrs Inman, successfully bringing a claim against Marks and Spencer. Initially they relied on their reputation for high standards. However, after a lengthy legal battle, they eventually conceded that they were responsible for Mrs Inman's illness after documents were produced showing the extent of asbestos within the store in question. Marks and Spencer is currently funding Mrs Inman's immunotherapy treatment but sadly, this is not an isolated case, with Marks and Spencer being taken to court in several other mesothelioma cases, some quietly settling, with others played out in the public domain.

Even into the 1970s, hygiene standards within the food industry fell far below what would be expected today and indeed, what was required in line with legislation at the time. Often, fire protection was prioritised above the risks to employees posed by asbestos exposure, as in Mr G's case.

Mr G worked as a carpenter for a well-known brewery chain. During the 1970s, he was required to install asbestos boarding for fire protection purposes within pubs owned by the brewery. Cutting the asbestos boards to size triggered the release of dust into Mr G's breathing space and as a result, he has since developed a non-malignant asbestos disease. His case is ongoing but the brewery's representatives have accepted responsibility for his illness.

Another client, Mike, worked as a chef within the catering department of a large university. Documents confirmed that the university buildings contained significant quantities of asbestos and Mike recalled disturbance of asbestos materials during day-to-day building maintenance. Given the pressured nature of mass catering, Mike was required to continue working within the kitchens whilst the works were ongoing and was accordingly unable to avoid inhaling the asbestos dust released.

Like Mrs Inman, Mike cleared up the asbestos dust and debris produced by the maintenance works and, like Marks and Spencer, the university in question initially denied liability. They argued that food production required a fastidiously clean environment, but later relented and made an out of court settlement offer, which Mike accepted.

Mike said: "It's scary to think that I came into contact with asbestos dust whilst working as a chef all those years ago, but I am pleased that in securing damages through the legal claim, my wife and I now have sufficient funds to move to a single storey home, where we will be closer to our family."

These cases, which arose within varying areas of the food sector demonstrate that, whilst on first glance, asbestos exposure within this industry may seem improbable, there are many ways in which such exposure arose and in which workers were very sadly let down by their employers. Any past employment within the food industry should therefore be taken into consideration where a patient has been diagnosed with mesothelioma and is considering making a benefits application or pursuing a legal claim.

ARMED FORCES

Mesothelioma UK commissions armed forces memorial sculpture

Mesothelioma UK has commissioned a design for a memorial sculpture to honour mesothelioma patients from the armed forces. Once funding is secured, the sculpture will be installed at the National Memorial Arboretum in Burton-upon-Trent, Staffordshire. The permanent memorial will honour all veterans, armed forces service men and women who have died from mesothelioma.

The planned sculpture is part of Mesothelioma UK's 'Supporting our Armed Forces' project that has captured the impact of mesothelioma amongst and our forces and established a bespoke service that provides information, advice and support specifically for armed forces veterans and serving personnel affected by mesothelioma.

The memorial is made up of more than 60 carved stone blocks representing the building blocks of life and public service. The blocks form a tower which, although damaged, is supported above and below. The supporting blocks represent the support offered by the charity.

The stone blocks are engraved with information about the charity, mesothelioma, asbestos and the armed forces. Blocks can be sponsored in memory of a loved one or supporters can make a donation to the charity to help fund the work.

To sponsor the memorial, visit www.mesothelioma.uk.com/armed-forces-memorial-donation/ or contact 0800 169 2409.

Brian Wallis, veteran and Mesothelioma UK Ambassador said: "It is an honour and privilege to be an Ambassador for Mesothelioma UK, especially as my late wife and I gave most of our working lives to Crown and Country before she died of mesothelioma in 2013. This memorial will provide an opportunity for families and loved ones to pay tribute to their fallen and I commend the project to you all.

"I am urging all those who have lost a loved one to this terrible disease to contribute to this unique memorial - as a tribute to their loved ones and to those who have cared for them during their illness."

Head of Services for Mesothelioma UK, Liz Darlison, commented: "Our Supporting our Armed Forces project has gone from strength to strength and we're eager to ensure there is a permanent memorial to honour armed forces personnel and veterans who lost their lives to mesothelioma.

"We're inviting anyone who has lost a loved one to sponsor a block in their memory or make any donation they can to help us fund this project."

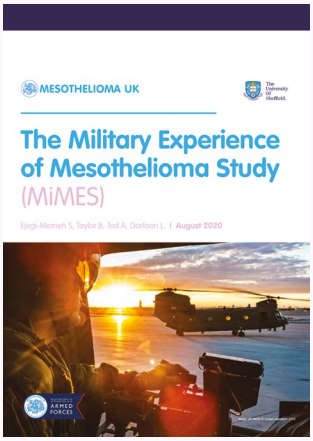
'Mesothelioma UK – Supporting our Armed Forces' virtual event

On 26 August 2020, the 'Mesothelioma UK – Supporting our Armed Forces' project team held a virtual event for key stakeholders from Armed Forces charities to healthcare professionals.

The event included the launch and presentation of the findings from the Military Experience of Mesothelioma Study (MiMES), which can be viewed at https://youtu.be/BAUdyDDme8M

MiMES research report summary

The Military Experience of Mesothelioma Study (MiMES) is now complete and the full report can be accessed on the Mesothelioma UK website.



Research aims
The aims of this mixed methods study were to:

- generate evidence on the incidence and prevalence of mesothelioma amongst British armed forces veterans,
- generate insights into their experiences and health/support needs
- identify how health professionals and support agencies can best support them

Methods
Quantitative data were derived from three data sources, the record of claims for the Armed Forces Compensation Scheme, a national dataset of clients receiving services from an Asbestos Support Group in the UK, and the Mesothelioma Outcomes, Research and Experience (MORE) survey conducted by Mesothelioma UK.

Qualitative data was collected by conducting semi-structured interviews with:

- 13 veterans living with mesothelioma, plus one person who was a contracted worker on an armed forces base
- 10 family members of veterans living with mesothelioma
- 8 professionals who work to care for and support mesothelioma patients and British armed forces veterans

Findings
The following key messages were generated from the study findings:

1. The data challenges assumptions regarding who has been exposed to asbestos whilst in the Armed Forces and raises awareness of the risk of such exposure
2. Occupational history taking requires skill and sensitivity for patients with an armed forces background. This can trigger emotional distress for patients, especially those who have experienced combat or trauma during their military career
3. Veterans' stoic approach may disguise their physical and emotional needs
4. Veterans require access to experts with experience of navigating the relevant health, legal and military systems
5. It is important to recognise and understand the veteran's mesothelioma experience from the perspective of family members when planning care and support
6. Veterans living with mesothelioma may prefer to support, and be supported by, other veterans
7. Some veterans perceive inequalities between their experience of living with mesothelioma and that of civilians
8. There remains a lack of awareness regarding asbestos exposure and concern about ongoing asbestos risk

These key messages have implications for practice that are presented in the final report. These focus on the legal, medical, financial and support needs and preferences of veterans and their families living with mesothelioma.

Conclusions
MiMES provides valuable insight into the experience of UK Armed Forces veterans living with mesothelioma. The findings and implications from the MiMES will help to raise awareness of the implications of the disease and provide some guidance for professionals working with veterans and their families living with mesothelioma.

The psychological effects of mesothelioma from the perspective of carers of UK Armed Forces veterans with mesothelioma

As part of the MiMES research, Mesothelioma UK is funding a project which aims to investigate the psychological effects of mesothelioma from the carer's perspective. Specifically, this study is looking at UK Armed Forces veterans and their carers/supporters.

The University of Sheffield PhD student, Virginia Sherborne, is currently recruiting participants for a study looking at the psychological effects of mesothelioma on UK military veterans from the carer's perspective. She is interested in hearing from anyone who is the main carer or supporter (unpaid) of a veteran who has a diagnosis of mesothelioma.

To count as a veteran, the patient needs to have served at least one day in the British Armed Forces (including reserves and National Service). Also included in the study are carers of veterans with mesothelioma who have sadly passed away, from any cause, within the last two years.

Anyone who would like to express an interest in having an interview (online, not face-to-face) can do so by calling the freephone information line on 0800 169 2409.

Mesothelioma UK – Supporting our Armed Forces shortlisted for national healthcare award

We're delighted to share the news that the 'Supporting our Armed Forces' project has been shortlisted for the HSJ (Health Service Journal) Awards, in the Military and Civilian Partnership Health category. Well done to all involved in this project. Winners will be announced in March 2021, so fingers crossed!

Action Meso launched to raise awareness about mesothelioma

A new project called Action Meso has been launched by the UK Mesothelioma Alliance to bring together the diverse mesothelioma community with a single voice.

It is the first time that so many patient support groups, charities, professional bodies, patients, carers, and healthcare and legal professionals have joined forces to raise awareness of mesothelioma.

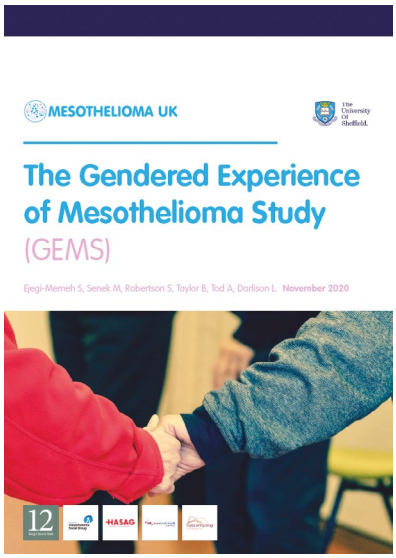
We are calling for action to be taken to eradicate this incurable but preventable disease through a range of initiatives, campaigns and the launch of the Action Meso website.

To find out more and sign up to the Action Meso mailing list, please register your interest at www.actionmeso.org

RESEARCH

New report published on gender differences in the experience of asbestos-related cancer

A study investigating the different experiences of men and women with mesothelioma has been completed. The results will now be shared with healthcare professionals and policy makers to make recommendations on how health, legal and social support services should best be delivered to be accessible and acceptable to both men and women.



Mesothelioma UK collaborated with the University of Sheffield on this research - the Gendered Experience of Mesothelioma Study (GEMS) – after consultation with health and legal professionals indicated that women may have a different experience to men in terms of awareness of the disease, diagnosis, access to treatment and compensation and legal processes.

Researchers interviewed patients and key findings included:

- High risk occupations for men differed from high risk occupations for women
- Women of all ages and younger men lacked awareness of the dangers of asbestos exposure
- Gender differences existed in the experiences of explanations and support provided at the time of diagnosis
- Men and women's roles within the family and society influenced how they coped with a diagnosis of mesothelioma
- Men and women had different ways of communicating with professionals along the mesothelioma pathway
- Familial and social expectations of men and women influenced their willingness to pursue civil compensation

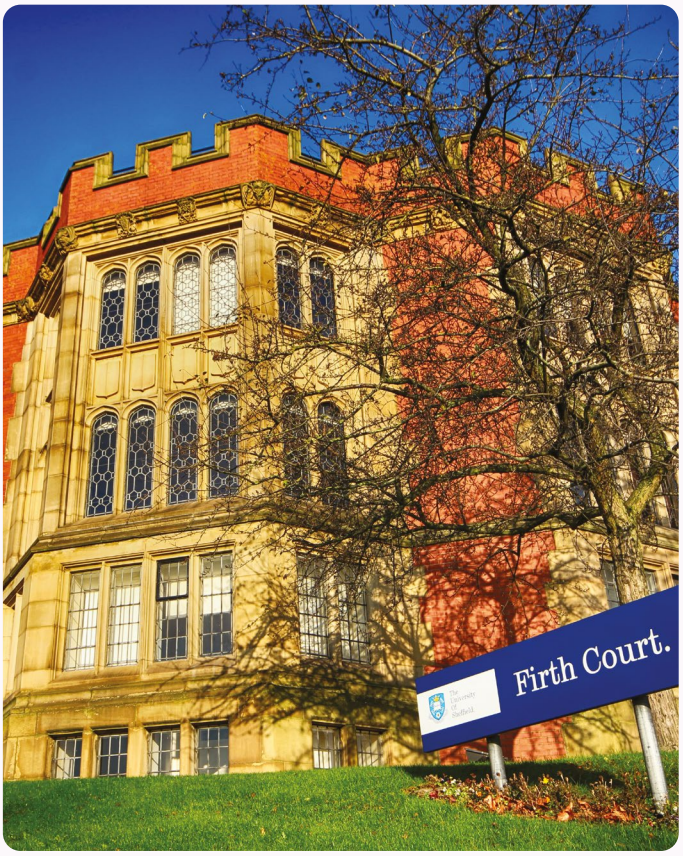
A full copy of the GEMS report, detailing the findings and recommendations, is now available at www.mesothelioma.uk.com/GEMS

Professor Angela Tod, Division of Nursing and Midwifery, University of Sheffield said: "We're so grateful to everyone who took part in this research which provides valuable insights into the experiences of women and men living with mesothelioma. The findings and implications from GEMS will provide some guidance and support for professionals working with men and women living with mesothelioma."

Liz Darlison, Head of Services for Mesothelioma UK added: "Mesothelioma UK, alongside the other funders of the research, realises how important this type of research is to improving the care and treatment for all patients. We're delighted that this report will give professionals information that will help them to provide the best service they can."

GEMS is a Mesothelioma UK collaborative study, supported by generous donations from 12 King's Bench Walk, HASAG, Irwin Mitchell, Mesothelioma UK, Papworth Mesothelioma Social Group, and Royds Withy King. GEMS was conducted by the Mesothelioma Patient Experience Research Group at the School of Nursing and Midwifery, University of Sheffield.

New mesothelioma research centre launched at the University of Sheffield



- The Mesothelioma UK Research Centre will be the first of its kind in the country dedicated to patient experience-based research
- The Sheffield centre will help to establish the gaps in existing knowledge and identify future priorities to better support patients and their families

The University of Sheffield is set to lead the way in pioneering patient-led cancer research after being specially selected to launch the first Mesothelioma UK Research Centre (MURC).

The new centre is funded by Mesothelioma UK and will be the first of its kind in the country to focus on experience-based research. This will be used to inform health professionals and support organisations on how to improve the vital support and care needed for mesothelioma patients, their family and carers.

The University Of Sheffield.

Mesothelioma is a terminal and aggressive cancer, with 50 per cent of patients dying within 12 months of diagnosis. The UK has the highest incidence of mesothelioma in the world with 2,700 new cases diagnosed each year.

Nine out of 10 cases are caused by exposure to asbestos which was used widely in the UK from the 1930s to the 1970s in buildings and building products such as insulation around pipework and boilers, insulation boards used as partitions or fire breaks, ceiling tiles and corrugated roofing sheets.

Director of the MURC, Professor Angela Mary Tod from University of Sheffield Health Sciences School, said: “Our work conducted through the Mesothelioma UK Research Centre will provide crucial information about what patients with mesothelioma and their families experience.

“Mesothelioma is a devastating disease which is caused by asbestos exposure in an overwhelming number of cases. This means families are often not only having to face the devastating diagnosis, but also the start of a legal battle for compensation which is an extremely daunting and emotional experience.

“Finding an effective treatment or a cure for the terrible disease is obviously the main priority for researchers and clinicians worldwide, but here in Sheffield, we are uniquely focused on patients’ experiences in order to drastically improve the support and care they receive.

“Our groundbreaking work will help to establish the gaps in existing knowledge and also help to identify future research priorities.

“The vision of the MURC is to conduct a portfolio of robust and rigorous research that will contribute to the way services are delivered. This research will have a reputation for excellence nationally and internationally and will be of benefit to the care of people diagnosed with mesothelioma and their families, relevant to the scientific cancer research progress, service development and patient and carer need, and inform policy.”

Hannah Ball, Advanced Nurse Practitioner in Lung Cancer and Mesothelioma and Mesothelioma Researcher, said: “Mesothelioma is an unusual cancer and a particularly difficult diagnosis for patients to deal with in that it’s cause is almost entirely due to previous exposure to asbestos, often many years before diagnosis.

“Learning that there is no known cure and the complex legal and financial issues many patients and their families have to deal with, coupled with the fact that they may have never heard of the disease until their diagnosis, all compound the inherent difficulties that come with a terminal diagnosis. Being a rarer cancer means finding expert support for research is challenging.

“The launch of the Mesothelioma UK Research Centre is incredibly exciting and will bring together a dedicated team of researchers to spearhead patient experience research into mesothelioma.

“Professor Angela Tod and her team at the University of Sheffield have been at the forefront of qualitative research in mesothelioma for many years now and I cannot think of a better and more informed team to be leading this initiative. This in turn will raise awareness and better understanding of the disease and inform policy makers to enable a real impact on patient care, not just nationally, but at an international level.”

The MURC builds on existing studies conducted in collaboration with the University of Sheffield including:

- Mesothelioma Outcomes, Research and Experience Study (MORE) - Mesothelioma UK’s second patient experience survey. More than 500 patients from across the UK took part in the study which examined the experience and outcomes, and highlights confidence and satisfaction across many across mesothelioma care
- The Military Experiences of Mesothelioma Study (MiMES) which aims to understand the experience, health and support needs of British armed forces personnel and veterans with mesothelioma, and identify how health and legal professionals and support agencies can best meet their needs
- The Mesothelioma Asbestos Guidance Study (MAGS) aimed to explore the experiences of presentation, diagnosis treatment and care for health workers with mesothelioma
- Mesothelioma Education Workers Study (MEWS) - developed as a critical account of the experiences of current and former school-based education workers with mesothelioma
- RadioMeso which identifies ways to improve the patient and family carer experience of receiving a diagnosis of mesothelioma

The MURC is keen to explore potential research collaborations and aims to link the growing number of academic and clinical researchers focusing on mesothelioma in the UK to enhance the impact studies can have on practice and policy. The Centre is already working with a number of international collaborators in South Africa and the United States in order to expand the research and its impact globally.

To find out more about the Mesothelioma UK Research Centre please visit: www.sheffield.ac.uk/murc

CLINICAL TRIALS

Dual Immunotherapy Prolongs Survival While Avoiding Chemotherapy in Malignant Pleural Mesothelioma

By Lorraine Creech, Mesothelioma UK Head of Nursing

The randomized phase III CheckMate 743 trial has broken new ground in malignant pleural mesothelioma (MPM) by establishing the benefit of a chemotherapy-free regimen in patients with previously untreated disease.

"This is the first positive randomized trial of dual immunotherapy in first-line treatment of patients with unresectable MPM, and therefore nivolumab plus ipilimumab should be considered as a new standard of care," commented lead investigator, Dr Paul Baas, MD, PhD.

Currently NICE (National Institute of Health and Care Excellence) is conducting a single technology appraisal on Nivolumab and Ipilimumab for untreated unresectable malignant pleural mesothelioma.

ATOMIC-Meso study sponsor is motivated to complete enrolment by August 2021

- ATOMIC-Meso Phase 2/3 study is a randomized, double-blind trial of ADI-PEG 20 or placebo in combination with pemetrexed and cisplatin (or carboplatin). ADIPemCis, is being studied as a first-line treatment for non-epithelioid MPM (biphasic and sarcomatoid subtypes) (ClinicalTrials.gov Identifier: NCT02709512)
- In a prior phase 1 study (NCT02029690), the ADIPemCis combination resulted in an encouraging overall response rate with prolonged overall survival in some patients, with non-epithelioid MPM and non-squamous non-small cell lung cancer
- ADI-PEG 20 deprives the cancer cells of arginine and is expected to make them more susceptible to the standard-of-care chemotherapy (pemetrexed and cisplatin/carboplatin)
- ADI-PEG 20 has been well tolerated, adverse effects are typically consistent with those of the chemotherapy alone
- This study is carried out at many sites throughout the UK and globally. A new UK site recently opened at University College London Hospital and an additional site will open soon at the University of Hull
- The CHECKMATE-743 trial treatment with the ipilimumab and nivolumab arm resulted in significantly longer overall survival compared to pemetrexed and cisplatin/carboplatin in the non-epithelioid subgroup. NICE has projected to publish their opinion on that study on 18 August 2021. As such, the ATOMIC-Meso study sponsor is motivated to complete enrollment prior to that date
- Now in the phase 3 portion, at the time of this update the study has 167 open spots remaining to reach the required 386 patients. Enrolment is currently planned to continue for at least the next year

PREDICT-Meso Network update

The PREDICT-Meso Accelerator Network aims to develop new research tools, resources and infrastructure to support current and future Malignant Pleural Mesothelioma (MPM) research over a five-year period.

An aim of the Network is to collaborate and share knowledge and data - helping to maximise the yield of knowledge and data gathered from individual sites and studies to better inform the overall understanding of MPM. The Network has already expanded beyond the initial project application members in the UK, Spain, Italy and Belgium to include new members from the US and Canada, and exciting new collaborations are on the horizon.

Closer to home, the PREDICT-Meso team has been enlisting sites across the UK for our clinical study Meso-ORIGINS, at which we hope to start recruitment next year. Meso-ORIGINS is an ambitious study to try and define in vivo the key biological events that drive or permit evolution of MPM, and subsequently allow development of more effective treatments and earlier interventions for the disease.

Meso-ORIGINS will recruit patients with benign asbestos associated pleural inflammation and follow their progression over two years, collecting repeat tissue samples in the minority who develop MPM and a sample of those who do not.

Creating these unique matched benign/MPM tissue pairs and aligning these with world-class pre-clinical research will allow us to define the driving (oncological) and/or permissive (immunological) events involved in the development of MPM.

PREDICT-Meso is now on Twitter. Please follow us at @PREDICT_Meso for further updates as this exciting project and Network moves forward.

BEAT-meso open

BEAT-meso (BEvacizumab and ATezolizumab in malignant pleural mesothelioma) is a multicentre randomised phase III trial. It compares atezolizumab plus bevacizumab and standard chemotherapy versus bevacizumab and standard chemotherapy as first-line treatment for advanced malignant pleural mesothelioma.

The trial remains open and organisers are keen to continue to see patients. For more information, contact BEAT-meso@etop-eu.org

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You shop. Amazon gives.

Consider Payroll Giving

Encouraging philanthropy in the workplace shows that the employer not only cares about its staff but also cares about its community. One way a company can do this is by setting up Payroll Giving - also known as Payday Giving, Give As You Earn or Workplace Giving.

This type of giving is one of the easiest ways to make a regular tax-free donation to a cause that you would like to support.

Payroll Giving is a scheme that enables employees to give a donation direct from their gross salary before tax deductions; the tax you would normally pay to the government can also be gifted to any registered charity that is recognised by HMRC, thus allowing UK employees to give more for less.

Payroll Giving is a valuable, long-term source of income for charities and regular donations through this scheme will help charities to make a lasting difference to those who need support. Signing up to the Payroll Giving Scheme has lots of benefits for the employer too.

Workplace philanthropy can have a positive effect on employees. Anecdotally, it has been shown that those companies who have registered with a Payroll Giving Scheme have helped to boost employee morale as it is a quick and easy way for people to give to their chosen cause. It can also aid staff recruitment as increasingly applicants want to know about a company's social responsibility and their ethical profile. Another benefit to the employer is any money that the company gives is tax-deductible.

Companies need to register with a Payroll Giving Agency (PGAs are regulated by HMRC) and can also be awarded a Payroll Giving Quality Mark Certificate accreditation which identifies businesses that are supportive of workplace philanthropy.

If you would like to support Mesothelioma UK in this way, ask your employer if they would be interested in being a member of the Payroll Giving Scheme. If you are an employer (it doesn't matter how big or small your company is) and you are interested in signing up, visit our website for more information at www.mesothelioma.uk.com/getting-involved/donate/. Alternatively, call us on 0800 169 2409.

Taking on the 20for20 Challenge

Mesothelioma UK recently joined forces with 19 other charities for lesser known cancers to create a unique and exciting 20-day challenge.

The idea was for people to raise sponsorship by doing a challenge relating to the number 20. The challenge was up to the participant and could be anything – walking every day for 20 days, running 20km, baking 20 cakes, cooking with 20 ingredients...the list is endless!

Always willing to get involved in supporting the charity, 20 of the Mesothelioma UK nurses also set themselves challenges from running and swimming to crafting and cooking. We hope you saw some of their challenges on our social media pages.

Thanks to the nurses and our ever-generous supporters who took part or donated, in particular some members of our legal panel, the 20for20 Challenge raised £725.

Team Horner - walking for Rusty

We sadly lost my Dad, Russell Horner, to a rare form of mesothelioma in January. My Dad was the strongest man we've ever known and we thought if anyone could fight it, it would be him but unfortunately, this wasn't the case. This is a cruel form of cancer (as is most) which acts quickly and aggressively.

The worst part of this cancer is because it is so rare, little is known about it and we must change that. So together with Russell's family, friends and former colleagues, we decided to set the challenge of completing the Yorkshire Three Peaks with the aim to raise as much money as possible for Mesothelioma UK. We had a fantastic day reminiscing and cherishing fond memories for such a special man. Alongside this, we managed to raise an amazing £6,065.05 (including Gift Aid), so thank you to all our supporters. Together Russell's family and friends will continue to raise money for this special charity.

Tamara's head shave in memory of Grandad

I'm Tamara and I recently shaved all of my hair off to raise money for Mesothelioma UK in memory of my grandad who passed away a couple of months ago. We were very close; he was diagnosed with mesothelioma three years ago and all of us got so much support during those difficult times. He fought long and hard and we all miss him so much.

Tamara's Grandad

Head shave in memory of Dad

My dad was diagnosed about four years ago but before he become ill, he was a very hard worker who worked for B&M Care which is a private company that runs residential/ nursing care homes for the elderly. He had been there for around 40 years.

I grew up going to work with him at the weekend and school holidays where possible, which led me into nursing. Dad was a carpenter by trade and an excellent one as well and soon became the maintenance manager; he loved his job. Dad was also a big pigeon fancier and flew pigeons from all over.

When dad got diagnosed, it broke my heart and many more as he was much loved, especially by his wife Andrea, who made dad's life so happy. Andrea was amazing. She looked after my dad so well. She kept so strong; I don't know how she did it as I was a mess. Dad tried to keep positive for his children and grandchildren but deep down he was tired and hurting so much and only Andrea saw how he really felt. Towards the end, dad didn't want us kids or grandchildren to see him. At the time I felt that was unfair, but I understand now why he wanted that.

My dad was the kindest person I knew and even till the end he worried about his family more than himself. Some days I would phone and dad was so bad that he couldn't even breathe when speaking so it was a quick hello and goodbye, just to put my mind at rest that he was still here. So, when dad did pass away, I decided to shave all my hair off for Mesothelioma UK as they were amazing and looked after my dad so well at Lister hospital. I managed to raise £750. I wish it was more but sadly that didn't happen. Mesothelioma UK deserves every penny.

Facebook fundraisers

If you have fundraised or plan to fundraise for us, why not think about joining our Facebook Fundraisers Group? It's a private group for people to share their fundraising stories, ideas, tips and questions. We will also post details in there of any fundraisers and challenges which you might be interested in. Find it under Groups on our main Facebook page.

Charlie & Billy's 4x4x48

In June 2019, our father was diagnosed with mesothelioma, a terminal lung cancer, caused from an exposure to asbestos. Unfortunately, 37 years ago, the same illness took the life of our grandfather (dad's dad). Asbestos was used for many years for the strengthening and fireproofing of many materials, and although banned in the UK in 1999, it is still present in many buildings across the country. China and Russia continue to use it religiously in the construction of new builds.

In support of Mesothelioma UK, we will be running four miles, every four hours, for 48 hours. This equates to two marathons in two days, and those who know us, know that although we like to train, WE HATE RUNNING. The lack of sleep coupled with newborns will be an added challenge to overcome. (Note: this was originally set up as a 182 coast-to-coast walk, and then changed to the 3-peaks challenge, however, the birth of Charlie's daughter and coronavirus restrictions put a stop to these!).

Elizabeth's 10K per day for Grandpa Peter Murphy

Peter worked as an engineer on the boats and naval ships in his younger days and was exposed to asbestos. When he retired, he lost his wife and then dedicated his time to looking after his disabled daughter who had a brain tumour at the age of four. He looked after her until she sadly passed away at the age of 55.

When she passed away, Peter became ill and found it hard to breathe. Shortly after, he was diagnosed with mesothelioma which was caused by the asbestos exposure during his engineer days. This caused holes within the lining of the lung and in April 2019, he was given only a month to live.

Peter was a strong fighter and had numerous trips to hospital to drain his lungs and eventually lost his battle to this cancer 13 months after his original diagnosis. He was 86 years old.

In his memory, I, his eldest granddaughter biked 10km per day all of July to raise money for this form of cancer that is not as well-known as others. I need a knee replacement, so it made it hard work, but I managed to stumble through and raise £400 to help others with mesothelioma.

Gordon & Linda Fee's golden wedding anniversary

When Gordon Fee was given his mesothelioma diagnosis in early September 2018, he told the overseeing consultant that he only had one thing on his bucket list; to celebrate his golden wedding. Upon finding out that this was 18 July 2020, the consultant shook her head, put her hand on Gordon's shoulder and stated that it would be highly unlikely that he would survive that long. She even suggested bringing the date forward!

A short time after this, a close family friend shared that during his prayer time, he had an overwhelming conviction that Gordon would survive until his golden wedding. This conviction remained with him throughout the next 21 months; despite a number of major medical setbacks associated with mesothelioma surgery and chemotherapy. Remarkably, Gordon fought back after these and experienced a period of improved well-being whilst latterly receiving palliative care since November 2019. With me (his wife Linda) accompanying him, he resumed distance cycling with the help of an e-bike and was managing to intersperse this with 3-4-mile walks until mid-May 2020.

Original plans to celebrate our golden wedding with family and friends on a river cruise down the Ouse in York were cancelled due to COVID 19. A fairly last-minute suggestion was then made to have a street party instead on our anniversary. This idea was embraced by our neighbours and became a much bigger event than we first envisioned. Gordon had spent a couple of weeks just beforehand in our local hospice receiving support with increased pain.

He was discharged the day before our anniversary and we had the added joy of getting our Australian daughter over to join our other two UK daughters only just in time with a day to spare.

The street party had a band on our front lawn playing 60s, 70s and 80s music, dancing on the street, bunting and balloons, children's games, PA system used for some wonderful speeches (with Gordon excelling), fabulous finger food, homemade elderflower champagne and smiles everywhere. Gordon and I requested donations to Mesothelioma UK instead of presents and were thrilled by the generosity of our neighbours, friends and family. The evening of our golden celebrations saw Gordon lying in bed with a huge grin on his face - he had achieved the one thing on his bucket list and blessed so many in doing so.

Sadly, Gordon was re-admitted to the hospice a few days later and died there on 24 July. He really left his mark on so many people and was able to retain his sense of humour, fighting spirit and positivity until his last few days.

Mesothelioma UK has been a great support to both Gordon and I; particularly, the local MESSY support group overseen by Mesothelioma UK nurse, Simon Bolton.

Thank you so much.

Sam's English Channel swim

In June this year, my dear husband passed away from mesothelioma. Such a cruel disease.

My 10-year-old grandson, Sam, loves swimming. He swims for his school squad at Parkside School in Cobham and also at Epsom District swimming club. When the pools closed this summer and swimming ceased, Sam started open water swimming in lakes to keep fit.

After completing initial 2km swims, Sam wanted to find a challenge to set himself during lockdown. He decided to take part in a 'virtual challenge' and chose to swim the English Channel, a total of 21 miles.

From cold, early morning starts at the lake, to late nights at the pool, Sam completed his virtual English Channel swim, completing 21 miles in 17 days.

I am so proud to be able to say that Sam has now raised £1,785.00 plus £330.50 gift aid, an amazing total of £2,115.15 for Mesothelioma UK, in memory of his very dear 'Silly Grampy' - Derek Marchant.

David's 40th London Marathon

I first met Lyn in 1999 when I joined the local male voice choir, The Chess Valley MVC. We both sang top tenor so sat next to each other in rehearsals and concerts. It was though our wonderful tours that both our wives became close friends and were part of our WAGS supporters at concerts in so many memorable venues. To name a selection, the Schoenberg Palace in Vienna, in the salt mine cathedral in Poland and the Mass in Krakow Cathedral. Possibly the most moving was singing Abide with Me at the Last Post ceremony at the Menin Gate.

As our family friendship grew, we joined Lyn and his wife Gwyneth on several holidays in Tenerife and Lanzarote. The photograph is of us enjoying a beer by the ferry port in Tenerife. A must on every holiday was crazy golf and having fits of giggles when we messed up. Our wives would chat and we were likened to two naughty school boys. An accolade we rather liked.

I have been lucky enough to run all 40 London marathons and this year, in memory of Lyn, it was an easy decision to raise money for Mesothelioma UK. I am delighted that so many supporters raised over £3,300 for such a great cause.

The summary of the day of the run is atrocious but just wonderful, too. The weather was awful, heavy rain all day and the borrowed watch reset to zero after reaching the quarter distance point. From then on, I was concerned how I was going to prove that I had run the whole 26.2 miles. However, I was saved as the watch did show the total steps 73,596 which has been accepted that I did go the whole way. Whew!! My time was slow (6:48) but I felt good at the end.

The day was wonderful because of all the support from family, friends and neighbours. Plus, a rolling escort of 20+ runners from my local park running group and running the last half-mile with my four grandchildren.

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

iMig 2021 Virtual
7-9 May 2021
https://imig2021.org

Mesothelioma Matters Webinars
Monthly
www.mesothelioma.uk.com/events/webinars

Ultra Challenge Series
2021

Winter Walk
27-28 February 2021

Easter 50
10 April 2021

Isle of Wight
1-2 May 2021

Jurassic Coast
15-16 May 2021

London2Brighton
29-30 May 2021

Lake District Challenge
12-13 June 2021

Cotswold Way
26-27 June 2021

Look out for the Vitality Big Half 2021 - details on the Mesothelioma UK website

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

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