Autumn Edition 2021

MESOTHELIOMA UK

MESOTHELIOMA MATTERS

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Fundraising from London Landmarks Half Marathon

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NEWS

Patient and Carer Day 2021

Our Patient and Carer Day will be virtual again this year and will take place on Friday 1 October. It's a chance to learn, share and 'meet' others with similar experiences via our virtual lunch breakout rooms, focusing on four different areas related to mesothelioma – carers, peritoneal mesothelioma, breathlessness and a lung health workshop.

By joining us online, guests will learn the latest on mesothelioma clinical trials, treatments and research from clinical experts, and hear personal stories from patients.

There will also be three question and answer panel sessions with expert speakers on the day. The agenda includes an overview of the coroner's inquest, a demonstration of the Mesothelioma UK clinical trials app, talks/presentation from the palliative care team, patient stories and an update from the Mesothelioma UK Research Centre.

This event is free for all to attend although a donation to support Mesothelioma UK would be greatly appreciated.

More details, the full programme and how to register can be found at www.mesothelioma.uk.com/patient-carer-day

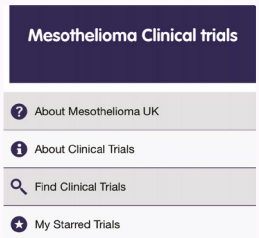
New Clinical Trials App

Mesothelioma UK has launched a mobile app to provide mesothelioma patients and healthcare professionals with easy access to up-to-date information on UK-wide clinical trials.

The app, available on the Apple App Store and Google Play Store, provides general information about trials, including different types and phases, things to consider before joining a trial and how to join.

Patients can then search for a trial which is suitable for their type and stage of mesothelioma. The app will tell patients everything they need to know including eligibility and exclusion criteria, treatment schedule, location and contact information.

Mesothelioma UK Clinical Nurse Specialist and Team Leader, Leah Taylor said: "For several years Mesothelioma UK has produced a quarterly update on the UK clinical trials along with our magazine, but we're excited to provide the app as it will give patients instant access to the latest information. We will continue the paper copy for those who prefer it, but we hope that many patients will download the app to have the updates at their fingertips.



"Clinical trials are vital if we are to make advances in the treatment and care of mesothelioma. While there is currently no cure for the disease, we are making great progress in terms of treatment, and patients taking part in clinical trials play a crucial role in that research."

The free app can be downloaded in the Apple App Store or Google Play Store by searching 'Mesothelioma UK'.

Our Mesothelioma Clinical Nurse Specialists

By Mesothelioma UK Head of Nursing, Lorraine Creech

We all want to get back to doing the things we love as the Covid-19 pandemic restrictions lift and in many ways. As Mesothelioma UK Clinical Nurse Specialists, we would like to return to the same face-to-face contact with our patients.

However, we are a long way off that in some respects, particularly as we remain wary about the future and what the winter months may hold, where the safety of our patients is paramount. In addition, virtual consultations have worked for many patients, meaning that they did not have to travel to outpatient appointments and potentially experience long waiting times.

Going forward, we're hopeful that we will be able to blend the old ways with the new and ensure that mesothelioma patients and their carers feel supported, physically and psychologically.

In my role as Head of Nursing at Mesothelioma UK, one of my prime goals is to have at least 38 Mesothelioma UK nurses in post by 2023. I am very proud to say that we are on track for this despite the difficulties the pandemic has thrown at us. Fundraising was severely depleted, as many events were unable to go ahead, and donations were reduced.

The pride I feel in staying on track, and recognising the calibre of our nurses, frequently sends me on a nostalgia-fest as I reflect on where Mesothelioma UK has come from and my involvement in it.

In thinking on this trajectory, I also often reflect on the blog of patient David Staley who used the quote of St Francis of Assisi, 'Start by doing what's necessary; then do what's possible; and suddenly you are doing the impossible.'

When patients are close to your heart, we often think of things they have said, and we learn so much by being alongside them.

Mesothelioma UK is a nurse-led initiative and an NHS success story. Liz Darlison MBE is now the Chief Executive Officer at Mesothelioma UK and a Mesothelioma Consultant Nurse at the University Hospitals of Leicester. Liz certainly is a trailblazer and the founder of Mesothelioma UK. Liz became the first mesothelioma nurse in 2002 and so much has happened since then.

We now have 34 nurses in post around the UK! We have some posts in sub specialisations such as peritoneal mesothelioma, thoracic surgical nursing, and the armed forces project. We aim to have a Mesothelioma UK Clinical Nurse Specialist in every Cancer Alliance in England, and a hub and spoke set up of CNSs in Scotland, Wales and Northern Ireland.

Liz calls the nurses our 'tour de force' and their skill and effort certainly amazes me. So, watch this space as we forge ahead and hopefully, with your support, we will reach 38 very soon.

If you are interested in hearing how you can support a nursing post, please contact the charity on 0800 169 2409 or email info@mesothelioma.uk.com

Support for all

Like many people and organisations during the pandemic, Mesothelioma UK has learnt to adapt to a more virtual world. Meetings, conferences, interviews and webinars have all had to be done online. It was important to us that we were able to continue to support our patients and carers and keep the mesothelioma community connected.

We already had active support groups on Facebook – a patient and carer group, a peritoneal mesothelioma group, an Armed Forces Group and a fundraisers group. In the absence of in-person support groups, we developed online meetings so that people could stay connected and still meet with others, albeit virtually.

We are holding regular Carers' Hour sessions online where carers can share their experiences and ask questions to our nurses. The sessions also include a guest speaker; topics have so far included claiming compensation, hospice care and the importance of self-care.

We also launched a support session specifically for younger carers and patients after feedback that some people felt that it would help them to talk to people of a similar age.

Our peritoneal mesothelioma clinical nurse specialist, Sam Westbrook, hosts regular online support groups for patients and carers who have this particular type of mesothelioma as they may experience different symptoms and have different treatments to other mesothelioma patients.

We hope that the support we offer – both in person and online – is helpful. We try to connect people to others who will be able to understand their experiences, not just in terms of a mesothelioma diagnosis but in terms of their background, age, type of mesothelioma, etc.

You can find out about the online events/groups we offer on our website or our social media. If you have any feedback or suggestions for us, please let us know at info@mesothelioma.uk.com

Christmas cards

It may seem like we've only just had summer, but Christmas will be here before we know it. As usual, we are selling our popular charity Christmas cards which are a great way to support us and send your best wishes to friends and family.

Cards are £4 per pack of 10 and postage will be charged at £3.95 for orders under £30. You can order online at www.mesothelioma.uk.com/shop or by completing the order form on the next page of this magazine and posting it to us at Mesothelioma UK, Unit 116, Greenacres, The Sidings, Station Road, Leicester, LE4 3BR.

2021 Christmas Card Order Form

1. Path to the Cottage

2. Special Delivery

3. Rockin Robin

4. Angel & Robin

5. Town Tree

6. Charity Bus

7. 3D Nativity

8. Geese Post

9. Down the Street

We have all this year's designs and more online at www.mesothelioma.uk.com where you can also purchase our cards. Please send this order form together with a cheque made payable to Mesothelioma UK: Mesothelioma UK, Unit 116, Greenacres, The Sidings, Station Road, Leicester, LE4 3BR

Name:
Address:
Postcode:
Contact Telephone Number:
Email Address:

Card	Card Title	Price per pack of 10	Number of Packs	Total Price
1	Path to the Cottage	£4.00		
2	Special Delivery	£4.00		
3	Rockin Robin	£4.00		
4	Angel & Robin	£4.00		
5	Town Tree	£4.00		
6	Charity Bus	£4.00		
7	3D Nativity	£4.00		
8	Geese Post	£4.00		
9	Down the Street	£4.00		

*We hold a large stock of cards, but some designs sell out early. Should this occur, please select a box below and tick to indicate what should be done with the balance of money.

Send alternative cards ☐ Refund ☐

Donation to Mesothelioma UK ☐

Subtotal	
P&P £3.95 (For orders under £30)	
Donation	
Total	

Movement for Good award winners

Mesothelioma UK has won a £1,000 Movement for Good award from Ecclesiastical Insurance Group, thanks to nominations from the public. The charity is one of 500 winners in specialist insurer Ecclesiastical's Movement for Good awards, which is giving £1 million to charities this summer.

Members of the public were invited to nominate causes close to their hearts, with 500 gifts of £1,000 available for donation. Over 13,000 charities were nominated by more than 210,000 members of the public.

Liz Darlison, Chief Executive Officer at Mesothelioma UK said: "We would like to thank Ecclesiastical Insurance Group for its Movement for Good initiative and for this award, which will help us to continue to support mesothelioma patients and their families. We would also like to thank all of our kind supporters for voting for us."

Mark Hews, Group Chief Executive of Ecclesiastical Insurance Group, says: "We would like to thank every single person who took the time to nominate a good cause as part of our Movement for Good awards. Ecclesiastical, the fourth largest corporate donor in the UK, is a unique financial services group. We are owned by a charity which means all available profits can be given to the good causes that are so important to our customers. As a company whose purpose is to contribute to the greater good of society, charitable giving is at the heart of our business. We know that £1,000 can make a huge difference to the incredible work that charities do and we're looking forward to seeing how this financial boost will change lives for the better."

Hugh James Mesothelioma Masterclass

Hugh James is hosting a Mesothelioma Masterclass study day aimed at Lung Cancer Clinical Nurse Specialists or those nurses who have a keen interest in the care and treatment of patients diagnosed with mesothelioma.

Rachel Thomas, who has recently joined Hugh James as a Mesothelioma Nurse Advisor, has led on the development of the Masterclass entitled: 'The Landscape of Mesothelioma in the Light of the Covid Pandemic'. The agenda will look at systemic anti-cancer treatment, surgery and radiotherapy treatments and the role of allied health care professionals in caring for mesothelioma patients.

Speakers include various experts in the treatment of mesothelioma and palliative care which includes both doctors, nurses and allied healthcare professionals.

This is a free event for nurses, and Hugh James are delighted to welcome Mesothelioma UK and HASAG as their chosen charities to come and highlight their invaluable work in supporting mesothelioma patients and their families. It will take place on 2 December 2021 in London.

Spaces are very limited and will be on a first come, first served basis but if you would like further information, please contact Rachel Thomas at rachel.thomas@hughjames.com

Norfolk Asbestos Awareness Campaign

Patients, carers and committee members of East of England Asbestos Patients Support Group (EEA-PSG) were pleased to accept an invitation by the Wells Community Hospital Trust (WCHT) to visit their new project.

Set in the rolling hills of the Norfolk coastal area and overlooking the North Sea, members were hosted by the staff of the Community Hospital in the newly refurbished café and landscaped gardens which are open to the public from Monday to Friday each week. Situated close to Holkham Hall, one of Norfolk's principal tourist attractions, this new facility is already proving popular with local groups and tourists.

EEA-PSG members were invited to display information leaflets supplied by Mesothelioma UK and group sponsors, Hugh James LLP. The display was well received by visitors to the café and hospital which provides facilities for a number of support groups and has dialysis, chiropody and hairdressing facilities on site amongst many other essential health services. The facility is supported by the NHS.

The EEA-PSG Norfolk support group will be visiting the facility on Friday 24 September and Friday 26 November at 11am. The WCHT has agreed to continue advertising EEA-PSG services on a reciprocal basis. Further details can be found at www.eastofenglandasbestos.co.uk

Calling all volunteers!

We recently launched a volunteer programme and are looking for new recruits. We have a range of volunteer roles available – from very hands-on to more behind the scenes. All volunteers will receive full support from the team and will be a valuable asset to the charity.

Volunteering can give people a real sense of purpose, achievement and the knowledge that you are doing something that will really help others. As a Mesothelioma UK volunteer, you will be supporting the vital work that we do for our patients and their families. You will be a representative of Mesothelioma UK and will be instrumental in spreading awareness of our charity and the disease.

Our aim is to support all our volunteers and ensure they feel valued, respected and part of a community.

The more hands-on roles are:

1. Community ambassador
2. Events volunteer
3. Spokesperson
4. Selling MUK goods to raise money

SCAN ME

If you prefer to work independently then don't worry, we have plenty of ways for you to get involved too. Check out our more hands-off roles:

1. Social media ambassador
2. Photography/videography volunteer
3. Proofreading
4. Selling goods to raise money (online)

If you think you would like to volunteer for us, please get in touch on 0800169 2409 or info@mesothelioma.uk.com, or scan the QR code above which will take you to the online volunteer form (www.mesothelioma.uk.com/volunteer-for-us/).

We look forward to welcoming you to our volunteering team!

Scottish Patient and Carer Event

The Scottish Mesothelioma Network (SMN) held its first virtual Patient and Carer Event before summer to provide patients and carers with the opportunity to hear the latest information on the network, new developments in treatment and clinical trials, patient experience and support, and pulmonary prehab and rehab information.

Over 90 delegates signed up for the event, which also included sessions on the emotional and financial support that the Scottish charities can provide as well as compensation and legal information from sponsors, Thompsons Solicitors.

The SMN, directed by Professor Kevin Blyth, Respiratory Physician at Glasgow's Queen Elizabeth Hospital and funded by partners Mesothelioma UK, Macmillan Cancer Support and NHS Scotland, is a network of dedicated mesothelioma clinical teams from five centres across Scotland. The centres ensure equity of treatment and access to clinical trials for mesothelioma patients across the country, whether they live in an island community or an urban environment. Since the network started in April 2019, the number of mesothelioma CNSs in Scotland has increased from none to five across each of the centres in Inverness, Edinburgh, Aberdeen, Dundee, and Glasgow.

Sessions on the day included an update on the progress of the SMN from Professor Kevin Blyth, latest information on immunotherapy and clinical trials from Dr Nicola Steele, Consultant Oncologist at the Beatson Cancer Centre in Glasgow, as well as Lucy Heycock, Meso CNS, interviewing mesothelioma patient, Nigel Shadwick about his experience of trials and treatment. There were also sessions from Action on Asbestos, Clydebank Asbestos Group and Asbestos Action Tayside on their important work campaigning and supporting patient and carers.

The last session included a presentation from Virginia Sherwood of the Mesothelioma UK Research Centre on the psychological impact of a rare cancer diagnosis and an interactive session from the Pulmonary Rehabilitation Team at Maggie's Inverness on managing breathlessness, as well as a pilates video from SMN Patient and Carer Representative and pilates teacher, Julie Roberts.

Delegates were given the opportunity to ask questions throughout. In the feedback survey that followed, one delegate commented: "I really enjoyed this event. It was informative and interesting with a wide range of topics explained well. I think the option of virtual events has allowed for more people to be able to attend and also dip in and out of areas where their interests are".

96 per cent of respondees also found the event very accessible and organised, and stated that they would be very likely to attend future events.

For more information on the network, visit www.scottishmesotheliomanetwork.scot.nhs.uk or follow @scotmesonet on Twitter.

AMD2021 biggest and best yet

For more than ten years, the first Friday in July has been Action Mesothelioma Day, a time to remember those affected by the disease, and raise awareness of mesothelioma and the dangers of asbestos. In 2020, the UK Mesothelioma Alliance (UKMA), which brings together the diverse mesothelioma community, organised the first national virtual event for AMD. At the height of the pandemic in 2020, hundreds of people came together online to hear a variety of speakers recognise and remember all those who have been affected by mesothelioma and to raise awareness about the impact that asbestos can have.

For 2021, a UKMA working group put together a brilliant programme and were honoured to have Kate Williams, broadcaster, academic and peritoneal mesothelioma patient, host the event and share some of her story.

One of the major objectives of this year's event was to encourage people to contact their local politicians to challenge the status quo guidance of managing asbestos in situ and to push for a phased programme of removal of asbestos from public buildings.

We were pleased to have supporting statements from politicians from England, Wales and Scotland, and encourage all readers to write to your MPs with these three questions:

1. In the past, asbestos 'in situ' has always been deemed as being safe if managed properly, however two recent studies by the HSE have shown there is a substantial increase in younger female teachers being diagnosed with mesothelioma. Given the findings in these more recent studies are you now concerned for the safety of our children in schools, especially when 80% of schools in the UK contain asbestos?

2. How will you support a phased programme to remove asbestos from all public buildings in the UK – starting with schools?

3. Mesothelioma and all other asbestos-related conditions are generally associated with older men who worked in traditional industry. Would you agree, given these recent HSE studies, that asbestos continues to take the lives, but now from a completely different demographic and so should be removed from all public buildings?

There followed a lively panel discussion on treatments and trials with experts from all over the UK representing oncology, surgical and nursing specialisms, with questions submitted in advance via Twitter and from the audience in real time.

We then heard from Nigel Shaddick, who took part in the groundbreaking Checkmate-743 trial, a double-immunotherapy trial that showed the most positive mesothelioma drug trial results for around 16 years.

In a moment of reflection, Ray Nye read his poem, written from a carer's perspective.

The smashing finale to this virtual event saw a group of patients, carers and support group representatives write a word on a plate that they associate with mesothelioma, to then see those plates and the words on them smash to the ground in a symbolic shattering of the emotions that those words can evoke.

To see the 2021 national virtual AMD on-demand, please visit www.actionmeso.org

ActionMeso is a UK Mesothelioma Alliance campaign driven by a working group including representatives from Action on Asbestos, Asbestos Awareness & Support Cymru, Asbestos Victims Support Groups Forum UK, British Thoracic Oncology Group, DAST, Erase Meso, Glynnis Gale Foundation, HASAG, Mavis Nye Foundation and Mesothelioma UK

Call for evidence - Health and Safety Executive's approach to asbestos management

The Work and Pensions Committee has launched an inquiry into how the Health & Safety Executive manages the continued presence of asbestos in buildings.

Despite the importation, supply and use of the material being banned in the UK since 1999, asbestos remains the largest single cause of work-related fatalities, with more than 5,000 deaths each year from diseases including mesothelioma, lung cancer and asbestosis.

The Committee raised concerns last year with the Government about the UK's policy on managing asbestos in buildings, following the publication of a report by think tank, Respublica. In response, the Minister for Employment confirmed that the HSE would be reviewing the effectiveness of the regulations for managing asbestos.

The Committee's inquiry will examine the current risks posed by asbestos in the workplace, the actions taken by HSE to mitigate them and how its approach compares to those taken in other countries. The results of the inquiry will feed into the executive's review.

The Committee wanted to hear views on questions including:

- What are the current risks posed by asbestos in the workplace? Which groups of workers are most at risk?
- How effective is the current legislative and regulatory framework for the management of asbestos?
- Does HSE keep adequate records of asbestos in public buildings?

The deadline for evidence for the committee closed on 17 September. We will publish the results of the inquiry in a future edition of Mesothelioma Matters.

Publications update

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 that you find this useful and thank you, UHL clinical librarians!

UHL Clinical Librarian Service
"bringing you the evidence"

New scientific research Immune checkpoint inhibitors a new player in the therapeutic game of mesothelioma: New reality with new challenges.
Author(s) Parikh ; Hendriks, Lizza E.L.; Bironzo, Paolo; Remon, Jordi
Source Cancer Treatment Reviews; Sep 2021; vol. 99

DNA Methylation as a Diagnostic Biomarker for Malignant Mesothelioma: A Systematic Review and Meta-Analysis.
Author(s) Vandenhoeck ; van Meerbeeck, Jan P.; Fransen, Erik; Raskin, Jo; Van Camp, Guy et al.
Source Journal of Thoracic Oncology; Sep 2021; vol. 16 (no. 9); p. 1461-1478

Essential role of the histone lysine demethylase KDM4A in the biology of malignant pleural mesothelioma (MPM).
Author(s) Lapidot ; Case, Abigail E.; Weisberg, Ellen L.; Meng, Chengcheng; Walker, Sarah R. et al.
Source British Journal of Cancer; Aug 2021; vol. 125 (no. 4); p. 582-592

Assessment of Global Trends in the Diagnosis of Mesothelioma From 1990 to 2017.
Author(s) Zhai ; Ruan, Jian; Zheng, Yi; Xiang, Dong; Li, Na et al.
Source JAMA Network Open; Aug 2021; vol. 4 (no. 8)

RRM1 and ERCC1 as biomarkers in patients with locally advanced and metastatic malignant pleural mesothelioma treated with continuous infusion of low-dose gemcitabine plus cisplatin.
Author(s) Muñoz-Montaño ; Muñiz-Hernández, Sae; Avilés-Salas, Alejandro; Catalán, Rodrigo; Lara-Mejía, Luis et al.
Source BMC Cancer; Aug 2021; vol. 21 (no. 1); p. 1-11
Available in full text at BMC Cancer from BioMed Central

Implementing CT tumor volume and CT pleural thickness into future staging systems for malignant pleural mesothelioma.
Author(s) Lauk ; Patella, Miriam; Neuer, Thomas; Battilana, Bianca; Frauenfelder, Thomas et al.
Source Cancer Imaging; Aug 2021; vol. 21 (no. 1); p. 1-8

Heterogeneity of treatment effects in malignant pleural mesothelioma.
Author(s) Di Maio ; Tagliamento, Marco
Source Lancet; Jul 2021; vol. 398 (no. 10297); p. 301-302

Hyperthermic Intrathoracic Chemoperfusion for Malignant Pleural Mesothelioma: Systematic Review and Meta-Analysis.
Author(s) Järvinen ; Paajanen, Juuso; Ilonen, Ilkka; Räsänen, Jari
Source Cancers; Jul 2021; vol. 13 (no. 14); p. 3637-3637

Integrating data from multidisciplinary Management of Malignant Pleural Mesothelioma: a cohort study.
Author(s) Saracino ; Bortolotto, Chandra; Tomaselli, Stefano; Fraolini, Elia; Bosio, Matteo et al.
Source BMC Cancer; Jul 2021; vol. 21 (no. 1); p. 1-9
Available in full text at BMC Cancer from BioMed Central

Ancillary Diagnostic Investigations in Malignant Pleural Mesothelioma.
Author(s) Dipper ; Maskell, Nick; Bibby, Anna
Source Cancers; Jul 2021; vol. 13 (no. 13); p. 3291-3291
Available in full text at Cancers from Europe PubMed Central - Open Access

Treatment patterns and outcomes of patients with advanced malignant pleural mesothelioma in a community practice setting.
Author(s) Waterhouse ; Nwokeji, Esmond D; Boyd, Marley; Penrod, John R; Espirito, Janet L et al.
Source Future Oncology; Jul 2021; vol. 17 (no. 19); p. 2439-2448
Available in full text at Future oncology (London, England) from Unpaywall

Qualitative studies and patient experience

Preliminary validation of a questionnaire assessing psychological distress in caregivers of patients with malignant mesothelioma: Mesothelioma Psychological Distress Tool-Caregivers.
Author(s): Bonafede, Michela; Chiorri, Carlo; Azzolina, Danila; Marinaccio, Alessandro; Migliore, Enrica; Mensi, Carolina; Chellini, Elisabetta; Romeo, Elisa; Grosso, Federica; Franzoi, Isabella Giulia; Granieri, Antonella; Guglielmucci, Fanny
Source: Psycho-oncology; Aug 2021

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

Effects of the COVID-19 pandemic on people with mesothelioma and their carers.
Author(s) Taylor ; Tod, Angela; Gardiner, Clare; Creech, Lorraine; Forde, Faye et al.
Source Cancer Nursing Practice; Jun 2021 ; p. 22-28
Available at Cancer Nursing Practice from Unpaywall

Understanding the palliative care needs and experiences of people with mesothelioma and their family carers: An integrative systematic review.
Author(s) Harrison ; Gardiner, Clare; Taylor, Bethany; Ejegi-Memeh, Stephanie; Darlison, Liz
Source Palliative Medicine; Jun 2021; vol. 35 (no. 6); p. 1039-1051
Available at Palliative medicine from Unpaywall

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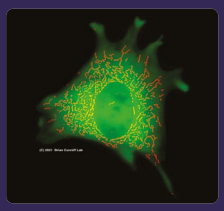
CLINICAL TRIALS

New class of drug targets intrapleural tumours



This first in human clinical trial, being carried out by RS Oncology, LLC aims to assess the safety and tolerability of a new experimental drug (called RSO-021) in patients with malignant pleural effusion due to mesothelioma and other solid tumours.

This new class of drugs alters the metabolism of mitochondria, which acts as the energy supply to cells. Normal and tumour cells have a difference in an enzyme fueling tumour growth. This novel drug targets this enzyme and inactivates pro-tumour activities.

RSO-021 is given locally through a catheter, directly into the space around the lungs every week until disease progression or unacceptable side effects are encountered.

The study consists of two parts. The first half is to determine the highest dose of the drug that patients can tolerate safely. The second half is designed to treat patients with a safe drug dose and determine if it is effective against tumour growth.

The study should be starting to enrol patients in the autumn of 2021 and will be run out of five or six UK hospitals in the following cities: London, Leicester, Manchester, Oxford, and Newcastle.

For more information, please speak to your Mesothelioma UK clinical nurse specialist.

Launch of MiST5

MiST5 is the fifth arm of the molecularly stratified umbrella clinical. This study examines the evolution of therapy through rational combination of drugs which have shown activity in previous studies.

In MiST1, it was recently reported in the Lancet Respiratory medicine that a so-called PARP inhibitor (rucaparib) targets cancer specific DNA repair deficiency. This agent alone was active. The team also recently reported results of the CONFIRM trial, which showed that single agent immunotherapy with anti PD1 drug nivolumab, improves survival. This was the first ever phase III trial to show this.

In MiST5, they have combined a pd1 inhibitor and PARP inhibitor. There is already evidence to suggest in other cancers, that these agents are synergistic.

The hope therefore is that the combination study, which is a collaboration with the UK company GSK using their niraparib (parp) and dolstarlamab (pd1) agents, will be more effective than either agent alone, providing an effective treatment option for patients. All patients will receive both drugs.

This study has recently opened in Leicester and the team are accepting referrals from across the UK. The study will also soon open in Manchester, Newcastle and Southampton.

RESEARCH

Mesothelioma UK Research Centre's Research Priority Exercise

The Mesothelioma UK Research Centre has been conducting a research prioritisation exercise (RPE) to identify unanswered questions about the mesothelioma patient and carer experience and to prioritise research areas of most importance.

The scope of the exercise is to focus on the mesothelioma patient and carer experience across the care pathway, from diagnosis to end of life care and bereavement support for loved ones.

This includes experience of the disease and its management, as well as experiences of care received, services provided and support given.

The exercise comprises three main stages:
1) Evidence synthesis: we reviewed the available literature to identify research gaps. This review has been submitted for peer review and we hope will be published soon
2) An online survey: we received 150 survey responses from patients, carers and professionals working to care, support and treat people living with mesothelioma in the UK
3) Consultation and ranking: The RPE steering group (16 individuals with mesothelioma expertise, including patients, carers and professionals) have completed ranking exercises and discussed the findings

We are now drafting the research priority statement and look forward to sharing this by October 2021. Thank you to everyone who has supported this exercise. We hope that the mesothelioma community will share and use the research priorities to improve the experiences of people living with mesothelioma.

MURC update

The Mesothelioma UK Research Centre was officially launched in 2020 and celebrated its first birthday on 1 July this year.

Current and new projects at the MURC include:
- Patient and Public Involvement (PPI) Panel
- Palliative care and the role of mesothelioma clinical nurse specialists
- The psychological effects of mesothelioma in the UK military context, the carers perspective
- Experiences of mesothelioma during the COVID-19 pandemic
- The experience of long-term survival in people affected by pleural mesothelioma and their carers
- Palliative care needs of military veterans (including mesothelioma)
- Exploring variability in patient pathway and experiences of care in peritoneal mesothelioma in the United Kingdom, in collaboration with Hampshire Hospitals NHS Foundation Trust
- New animation summarising findings from the GEMS study

If you would like regular updates about the research activities of the Centre, please sign up to the circulation list at www.sheffield.ac.uk/murc/about-us

The MURC would like to say thank you to all the people who have supported and participated in its studies. They are very grateful for the time, experiences and views that you have shared.

APPOINTMENTS

New Clinical Nurse Specialist in Wales

Sam Williams has been appointed as a Mesothelioma UK Clinical Nurse Specialist (CNS) to provide nursing care and support for mesothelioma patients in the areas of Blaenau Gwent, Caerphilly,Monmouthshire, Newport, Torfaen and South Powys.

Sam Williams

Sam will be based at the Aneurin Bevan University Health Board (UHB). She is the second Mesothelioma UK nurse in Wales and her appointment marks the first step in creating a hub and spoke network of Mesothelioma UK nurses across Wales, as part of the charity's Project Wales.

The need for more CNSs in Wales is evident from the high incidence of mesothelioma cases – the Aneurin Bevan region having the highest incidence in the country.

Project Wales aims to ensure that more support is available for patients and that there is an increased knowledge of mesothelioma amongst healthcare professionals across Wales.

Sam will work with Mesothelioma UK CNS and Lead for Project Wales, Sarah Morgan, to support patients and carers, and to raise the profile of mesothelioma and the difficulties faced by patients trying to access care and treatment in Wales.

In this Mesothelioma UK adopted post, Sam will assist in multidisciplinary teamworking to ensure that patients have access to the best treatment, care and clinical trials available.

Sam will share her knowledge and understanding of mesothelioma with other healthcare professionals in Wales to increase support for, and engagement with, mesothelioma patients in Wales.

Sarah Morgan, Mesothelioma CNS and Project Wales Lead, added: "I am delighted that Sam is joining Mesothelioma UK and Project Wales. The project has made good progress already in raising awareness of mesothelioma and the need for better access to care.

Sarah Morgan

"I look forward to working with Sam and our colleagues throughout Wales to improve services for all those affected by mesothelioma."

New Information Officer appointed

Joelle Kirby has been appointed as Mesothelioma UK's Senior Information Officer, joining the operations team at our Leicestershire base.

Joelle's priorities will be to build on our excellent reputation for providing information to mesothelioma patients and carers. Joelle will ensure that the information we provide, both online and in print, is relevant, evidence-based and clearly communicated.

The need for reliable information is vital for patients and carers, especially those newly diagnosed with mesothelioma.

Joelle is a qualified librarian and spent a number of years working for the NHS as a clinical librarian, for both Barts Health NHS Trust London and the Central and North West London NHS Trust. In these roles, she would accompany clinicians on ward rounds and access information to support the medical team and answer patient questions.

It was through this work that she became interested in health research, in particular making it accessible to as wide an audience as possible.

Joelle went on to work for the Royal Marsden, writing and editing their cancer information. She has also worked in a freelance capacity writing healthcare research summaries, making often complex health information more easily understandable.

Commenting on her new role, Joelle said: "I look forward to contributing to the fantastic work that Mesothelioma UK does. We've already got an excellent range of patient information and I am keen to help it develop and continue to support those affected by mesothelioma."

Welcome to Leah

Leah Scrimshire has joined Mesothelioma UK's operations team as a Junior Fundraising Assistant.

We welcomed Leah to the charity in August to strengthen our fundraising team by supporting our fundraisers and developing our fundraising platforms.

After working for the grounds team at Leicester City Football Club for three years, Leah decided on a career change and felt that the new role at Mesothelioma UK would be something she would enjoy and would utilise her IT skills.

Leah said: "I wanted a complete career change by getting into something which was more IT based, as I loved that subject at school. As soon as I saw the job advert that Mesothelioma UK published online, I knew it was something I would enjoy, and even more so once I began learning about the work the team here does to help people as well. I knew it would be a fantastic opportunity to learn things I wouldn't get the chance to otherwise.

"I am looking forward to learning even more within the role. Every day there is something new to learn which makes the role very versatile and exciting, so I am just looking forward to that continuing!"

Leah's main responsibilities include making sure the fundraising database is kept up-to-date, packing and sending orders from the online shop, responding to fundraisers and investigating different fundraising platforms.

ARMED FORCES

Recognising the contribution of ex-forces in business

Carolyn MacRae, Mesothelioma UK's Nurse Team Leader for Scotland, joined a key supporter of the charity at the second annual Scottish edition of the Ex-Forces in Business Awards.

Ensafe is the UK's fastest growing asbestos consultancy, environmental and risk management provider, and has supported Mesothelioma UK through donations to our Armed Forces Memorial campaign.

Carolyn joined Ensafe's Operations Manager (Scotland), Christopher Boyle, who was a finalist in the Inspiration of the Year award, and his colleague, Andy Thornhill at the ceremony.

The awards are the world's largest celebration of veterans in second careers, showcasing the value that military-gained skills and values bring to employers in Scotland.

Christopher said: "I was delighted that Carolyn could join us at this prestigious event. Ensafe is committed to supporting Mesothelioma UK and its work in raising awareness of the dangers of asbestos exposure.

"Unbeknownst to me, my role as a former Naval Airman Aircraft Handler meant that we would be coming into contact with asbestos in training, day to day duties and also on-board ship. This is one of the reasons that I have a passion to help raise awareness of asbestos and its dangers to active and ex-service members."

For more information or to donate to the Mesothelioma UK Armed Forces Memorial, visit www.mesothelioma.uk.com/armed-forces-memorial/

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AFE
ASBESTOS SURVEYING, PROJECT MANAGEMENT, HEALTH & SAFETY AND TRAINING

Mesothelioma UK's 'Supporting our Armed Forces' project wins national award

We were proud to announce in the spring edition of the magazine Mesothelioma UK's 'Supporting our Armed Forces' project had been shortlisted for the Military and Civilian Health Partnership Award at the 2020 HSJ Awards.

We are even more proud to announce that we won this very prestigious award, recognising an outstanding contribution to healthcare. This really highlights the success of the project in raising the awareness of asbestos exposure and mesothelioma in military personnel and veterans.

The awards ceremony was hosted by comedian Lenny Henry and we were able to join over 4,500 health and social care staff who joined proceedings online.

The judges said: "We felt this was an all-round package of care based on a well-researched evidence base which has also influenced government policy in the sector. They clearly identified the distinct issues related to military service which impacts upon their clients and have developed strategies to address these distinct challenges.

"The team has taken the clinical and welfare elements of their existing service and adapted these to meet the needs of the military community. The judges want to congratulate an enthusiastic and dedicated team who show ambition, drive and the expertise to achieve even greater things. This was an outstanding project with far reaching impact."

For further information and to keep up to date with the latest news on the project and the fundraising for the memorial visit the Mesothelioma UK website and the dedicated Facebook groups.

Fundraising continues for the memorial to armed forces personnel and veterans affected by mesothelioma and asbestos, to be located at the National Arboretum in Staffordshire. We are over halfway to the total needed.

The stone blocks that make up the memorial are engraved with information about the charity, mesothelioma, asbestos and the armed forces. You can donate any amount towards the memorial or sponsor a block, perhaps in memory of a loved one or colleague.

For more information on how you can support the fundraising campaign, call 0800 169 2409 or via www.mesothelioma.uk.com/armed-forces-memorial/

LEGAL PANEL

How mesothelioma patients are benefiting from clinical trials and immunotherapy

By Phoebe Osborne, Senior Associate in the asbestos team at Hugh James

It's great to see huge strides being made in immunotherapy and accessing this kind of treatment is important to mesothelioma patients.

But time is of the essence.

Before a new treatment can be approved by NICE, these drugs are meticulously tested to ensure their effectiveness, with many trials requiring years of research, and willing participants, before being made available on the NHS.

This places a huge burden on patients and their families. They often don't have the funds to pay for private treatment, which is costly. They also don't have the luxury of time, as mesothelioma is an extremely aggressive form of cancer, and we've seen many patients diagnosed during the COVID-19 pandemic, presenting late to their oncologists.

So, taking part in clinical trials is sometimes the only way patients can access certain potentially life extending drugs, before the legal claim can be concluded and future treatment secured within the claim.

At Hugh James, we know how important it is to obtain a future medical treatment costs order with the courts, wherever possible, as part of a legal claim settlement, to provide the necessary funds. It can potentially give our clients and their families valuable extra months, or even years, of progression-free survival, often with tumour reduction, leading to an overall improvement in quality of life.

Our client, David Squires, has benefited in this way.

We helped him pursue a legal claim against his former employer, G.B. Brundenell Ltd, in Cambridgeshire, where he was exposed to asbestos in the 1970s when working as an apprentice carpenter.

We secured a six-figure settlement, together with provision for future non-NHS private medical treatment via a Court Order. This means, if David requires treatment outside of a clinical trial, this can be funded privately via his settlement.

It was a month after his stage 4 diagnosis when David approached me to take up his case. I signposted him to the Mesothelioma UK Nurse at Royal Papworth and shortly after he was told about the BEAT-Meso clinical trial at Addenbrooke's Hospital, and he enrolled straight away.

As his civil legal claim progressed, David stoically embarked on further clinical trials at Addenbrooke's, eventually exhausting all local clinical trial options available to him by October 2020. By November 2020, David's treating oncology team referred him to Professor Dean Fennell at the Leicester Cancer Research Centre to be considered for enrolment on the MiST3 clinical trial.

David has responded remarkably well to this clinical trial and now wants to tell others about his experiences.

Here's David's story:

Before being enrolled on MiST3, I felt so worried about my future and that of my family. I was angry that my former employers were denying liability for my exposure to asbestos and my prospects looked bleak.

I discussed at length, with my treating oncologist at Cambridge, my desire to access all clinical trials - even if it meant me travelling outside of Cambridgeshire. I was desperate to do anything to extend my life expectancy.

Dr Gilligan and Dr Bruno De Paula at Addenbrooke's responded to my enthusiasm. Since they referred me to meet with Professor Dean Fennell and the team at Leicester, I've been utterly amazed at the care provided by the NHS during the pandemic.

All throughout COVID-19, I've attended trial and I'm continually overwhelmed at the dedication of the nurses and oncologists involved in my ongoing care, both locally and at Leicester.

I've seen how my own immune system has responded under the MiST3* trial, as has my wife and family. Within a few months of starting this treatment, my three tumour areas have dramatically shrunk in size. I'm absolutely overjoyed and I still can't believe the massive effects this combination of immunotherapy drugs is having on me - the tumours have shrunk to a fraction of the size – from 6cm to 1cm.

Although I'm still experiencing tiredness and have struggled with some side-effects, I'm back playing golf and walking my dog; activities that last year I was unable to do at points. Now the COVID-19 restrictions have lifted and my civil legal claim is settled, I'm determined to enjoy quality time with my family in between treatments and make the most of the time my family and I worried we would not have together.

Under the MiST3 clinical trial, I regularly undergo CT scans. I obviously feel anxious before every scan, but I'm overjoyed to see there has been shrinkage of my mesothelioma tumours. I hope my immune system will continue to respond in this way.

When I was first diagnosed, I was given 12 months to live but I am continuing to outlive my prognosis and I'm determined to stay on this clinical trial for as long as possible so that I can continue to enjoy quality time with my family and enjoy my hobbies.

I would always suggest to someone newly diagnosed with mesothelioma to ask lots of questions and meet with other people going through the same thing. By meeting others diagnosed with mesothelioma at a local patient support group and going online, I have heard about other people's experiences of clinical trials, including Mavis Nye, and it has given me the courage to take part, something I may not have done if I had not learnt of other people's experiences.

My family and I all feel extremely grateful to our NHS and to the clinical trials team locally and at Leicester. As dreadful as this diagnosis can be, I feel proud to be involved in shaping the care and treatment of future mesothelioma patients who may not have the financial means or grounds to make a legal claim. I want to ensure there's equitable access to the same medical treatments, whether privately or via the NHS, and hopefully my participation in the MiST3 clinical trial will lead to a new future standard of care.

*MiST trials have been funded by a donation to the BLF from the Victor Dahdaleh Foundation.

Time for change – why we need a pan-UK approach to bereavement damages for asbestos

Nicola Harrison, an **asbestos specialist and partner** at social justice law firm **Thompsons Solicitors**, calls on the UK government to adopt Scotland's 'caring and conscientious' approach to bereavement damages across England, Wales and Northern Ireland.

Losing a loved one because of an asbestos disease is always devastating for those families affected. Employers knew of the risks of asbestos for decades, yet many continued to use the dangerous substance until it was finally banned more than 20 years ago. As a result, thousands of people continue to suffer unnecessarily with asbestos illnesses each year.

In these scenarios, the families want a legal process that is clear and simple. While our asbestos experts will guide grieving families through a legal claim with clarity and compassion, the reality is that there is a postcode lottery for the level of support you can receive depending on where you live in the UK.

But first we need to look at what a bereavement award is and why there are differences across the UK's four nations.

What is a bereavement award?

The Fatal Accidents Act 1976 outlined a set of strict criteria on who can claim compensation – the bereavement award - if someone has died as a result of accident or illness at work in England and Wales. A year later, the Fatal Accidents Order 1977 was established in Northern Ireland.

This means that, in these three countries, you can only claim if you are:

- A spouse or civil partner of the deceased; or
- The parent of a child who died while they were under the age of 18 – which will not be relevant for asbestos cases.

After significant pressure and a 2017 Court of Appeal judgment, the government finally added that, from 2020, cohabiting partners who have lived together for at least two years can claim a bereavement award.

How much do you receive?

Across all UK nations (except Scotland) there is a fixed rate. In England and Wales this is £15,120, and in Northern Ireland it is £15,100. While these have increased in recent years, a fixed rate is still far too rigid, as it fails to consider how any unnecessary death will impact families in different ways.

So how is Scotland different?

The law is significantly more flexible in Scotland compared to the other three UK nations. Whereas in England, Wales and Northern Ireland the only people considered are spouses, civil partners, those who have cohabited for two years minimum and parents of under 18s, Scottish law takes into account the wider family and the emotional and financial impact it may have had on them.

In addition to those listed above, Scottish law also permits bereavement damages for:

- Children of the deceased;
- Grandchildren of the deceased;
- Siblings of the deceased;
- Partners of the deceased – regardless of whether they've cohabited for two years or not; and
- Any parent – not just those whose child died while under the age of 18.

Put simply, Scottish law recognises the close bond that families have in a caring and conscientious way that the rigid and uncaring laws across the rest of the UK do not.

Not only that, but all deaths are treated on a case-by-case basis. Subject to the age of the deceased person, their life-expectancy and the relationship with the relative, the bereavement award is likely to fall within the following ranges:

- Spouse / Partner: £60,000 - £100,000
- Children / Stepchildren: £30,000 - £60,000
- Grandchildren / Step-grandchildren: £5,000 - £30,000
- Siblings: £10,000 - £50,000
- Parents: £30,000 - £100,000
- Grandparents: £5,000 - £30,000

While there is no upper limit in Scottish law, even looking at the lower end of the bracket, it is evidently clear that grieving families in Scotland will almost certainly get a more substantial – and fairer – settlement than those in England, Wales and Northern Ireland.

In addition, the above range does not only apply to relatives living in Scotland. If the exposure happened in Scotland, all relatives would benefit from Scottish damages even if they live in England.

Case in point

One of our asbestos specialists in Liverpool is supporting the family of a man who was exposed to asbestos both in the UK and Scotland. While the compensation claim was the same in England as the rest of the UK, the family would not have been able to secure a bereavement award in England as the man was a widower. However, his daughter has been able to pursue a bereavement award in Scotland – meaning she could potentially receive upwards of £30,000.

Sadly, for those UK residents who have no link to Scotland, they have no choice but to take the paltry fixed rate – if they're even lucky enough to be eligible for that.

What's next?

Our asbestos experts echo the view of the Association of Personal Injury Lawyers (APIL), which is continuing to campaign against the unnecessary postcode lottery in bereavement damages.

Nonetheless, the UK government has largely ignored calls to modernise the process, even when it had the perfect chance to do so when the revisions were made to the Fatal Accidents Act 1976 in England and Wales last year. So only time will tell on whether it will bow to pressure now or in the future.

If you have been affected by mesothelioma, you should speak to a specialist solicitor as soon as possible. Find out more on the Mesothelioma UK website.

"Too close to home"

By Adrian Budgen, Partner at Irwin Mitchell

On 2 April 1996, a landmark judgment in favour of two Leeds residents, brought up in the shadow of an asbestos factory, was handed down by the Court of Appeal. Repercussions of the Court's decision in the case of Margereson and Hancock v JW Roberts Limited would echo across the UK, and as far afield as South Africa. The two claimants had fought to prove that Turner & Newall (T&N), JW Roberts' parent company, had failed in their duty of care, not just to their employees but also to those like June Hancock and Arthur Margereson, who had lived near to the Defendant's Armley factory.

June, who was born in 1936, grew up in Armley and attended Armley Park School; her mother, Maie, also had a sweet shop located close to the asbestos factory on Canal Road in Armley. As a child, like so many other children in the neighbourhood, June played with asbestos which was blown out of the factory's roof vents and 'swirled like snowflakes' through the surrounding streets, drifting in piles on windowsills and other surfaces. The factory's loading bays were 'like a magnet' to local children who would regularly gather to play hopscotch and roll marbles and spin tops on the flat surface of the loading bays, as the area was quite hilly. Children would go to the local butcher's shop and ask for a blown-up pig's bladder which they would use as a football.

They would also jump on the bales of asbestos which were placed on the loading bays and only occasionally be shooed away by the foremen. Innocent childhood games; but with a very dangerous legacy.

As part of our legal investigation, we interviewed a great many people who had lived in the area; we wrote to everyone on the electoral roll and also wrote to the playwright, Alan Bennett, and author, Barbara Taylor-Bradford, who had grown up in Armley. We also had to pore over many thousands of documents from Turner & Newall's own archives, which T&N tried very hard to withhold, and we were assisted by American lawyers acting for Chase Manhattan Bank in New York, whose high-rise building in Manhattan was riddled with asbestos installed by Turner & Newall. It was a mammoth task.

An old aerial photograph of Armley Clock School (adjacent to Canal Road and situated slightly higher than the factory) was unearthed by my colleague, Rachel Pairman, and it showed the playground covered in dust like a carpet of snow; the school children would play outside and the younger ones would even take an afternoon nap on little camp beds in the playground when the weather was fine. Rachel was later congratulated by the trial judge, Mr Justice Holland, for finding the photograph.

During the second half of the last century, hundreds of Armley residents paid a terrible price. The area was found to have the highest UK incidence of mesothelioma, which is almost always associated with asbestos exposure, and with a normal latency (incubation) period of several decades. June Hancock's own mother, Maie Gelder, very sadly died of mesothelioma in 1982. When June was diagnosed with the terrible illness in late 1993, she vowed to take on the multinational company (T&N) whose negligence she believed had caused her mother's premature death and would, likewise, rob her of her old age and seeing the births of her grandchildren. "Two in one family is too many," she said poignantly.

The Armley factory began producing textiles in 1874; some 20 years later, having been acquired by the Turner & Newall group, JW Roberts embraced asbestos technology and it went on to become one of the country's biggest producers of asbestos insulation and asbestos-containing fireproofing products (in particular sprayed 'limpet' asbestos) exporting to some 60 countries worldwide.

Tragically, for the residents and their families who were so badly affected, the factory was located in a densely populated area with back-to-back terraced housing encircling the industrial site. The company would later claim that it could not have known about the dangerous effects of asbestos exposure until after the Leeds factory closed its gates in 1959, well beyond the time when June Hancock and Arthur Margereson played in Armley's dust-covered streets.

Local doctors who recorded the effects of these industrial processes told a different story. The UK's first-named asbestos victim was Nellie Kershaw who left school at the age of 12 to work briefly in a cotton mill and then in Turner Brothers Asbestos (TBA's) mill, retiring of ill health in 1922 and dying two years later, at the age of 33, of asbestosis. As a result of Nellie's death, and others like it, the UK's first asbestos regulations were introduced in 1931.

It was in order to comply with these regulations that the factory owner (JW Roberts/T&N) said that it pumped asbestos out through the factory's ventilation system and into the surrounding neighbourhood, with devastating consequences.

T&N's lawyers argued, at the six week-long trial in Leeds High Court in the summer of 1995, that it did not have specific knowledge of the risks associated with the asbestos cancer, mesothelioma, until the mid-1960s; they also argued that their responsibilities extended only to their workforce, conveniently overlooking the fact that, in the process of sucking dangerous asbestos dust out of the factory in Armley in order to comply with the regulations in force, and as a consequence polluting the whole neighbourhood, they had exposed many hundreds (if not thousands) of people and children to the same deadly threat.

In finding in favour of June Hancock and Arthur Margereson (represented by his widow Evelyn) in October 1995, Mr Justice Holland saw off the company. The trial judge, in his 226-page judgment, concluded that T&N did indeed owe a duty of care to those living in the immediate vicinity of the Canal Road factory and to those former children (like June) who played on the factory's loading bays, 'tearing down' the factory walls.

It was a landmark judgment and the Defendant immediately signalled that it would appeal against Mr Justice Holland's decision. He had severely criticised T&N saying that it had contested the claims 'by every means possible, legitimate or otherwise, to obstruct the Plaintiffs' road… and to wear the Plaintiffs down by attrition', likening the litigation to a 'David v Goliath' battle.

It was the first case in the UK where a serious physical injury was found to have been caused by industrial environmental pollution. The implications for the defendant company, which saw its share price fall dramatically, were such that they felt compelled to appeal. The appeal was fast-tracked because June was very unwell. The case was heard at the end of March 1996 in a two-day hearing in London (June was present throughout) and the appeal court judges concurred with Mr Justice Holland and stated that the factory owner's guilty knowledge of asbestos went back before 1925, well before June was born. T&N was refused permission to appeal to the House of Lords. And so it ended.

Thus it was that the Goliath of a British multinational was brought to heel by a personal secretary from Bramley in Leeds. "It proves that no matter how small you are, you can fight"; said June, "and no matter how big you are, you can lose."

I am very proud, together with a number of my colleagues who still work at Irwin Mitchell some 26 years later, to have been able to play a part in making such a significant contribution on behalf of June's family, and many more families in the Armley area, and to have been part of achieving justice for thousands of victims of asbestos disease in the UK.

June's family, myself and her treating consultant, Dr Martin Muers, helped to establish the June Hancock Mesothelioma Research Fund shortly after June died in 1997; it was the first mesothelioma research charity to be formed in the UK and its vital work continues to this day.

The Meso Christmas Carol Off

Come and join Mesothelioma UK for the 2021 'Meso Christmas Carol Off'. It's so easy to take part and there's lots of fun to be had, and this year, you get to meet up! Sign up, choose your song and get meeting or Zooming, the choice is yours! And when your performance is complete, send your video entry for judging!

There are three categories you can enter!
Best Vocal Harmony
For all those budding singers

Best Performance & Musicality
For those who play an instrument(s)

Best Entertainment & Presence
For those a little lacking in the singing and instrument playing department, just dress yourselves up and perform

Anyone can join in this fun event at any age! And it doesn't matter where you are - Zoom will still bring you together and spread some Christmas cheer.

The Rules

- Teams can enter of any size and any age, choose your Team Leader
- Each adult to donate £5.00 to take part (children under 18 go free)
- Donations to be paid by Team Leader for all adult team members on registration (these can be added to if adding more members to the team)
- Teams can sign up on the website
- Once registration has been completed the Team Leader can choose a song from Mesothelioma UK's list of popular Christmas carols/songs these will be given on a first come first served basis
- Each Team Leader will receive a song sheet via email
- On Entry choose your Category
    - o **Best Vocal Harmony**
    - o **Best Performance/Musicality**
    - o **Best Entertainment/Presence**
- All entries to be in by midnight on 10 December 2021
- A panel of independent judges will vote for the three winning teams
- The winning entries will be uploaded to the Mesothelioma UK website Christmas page from 17-31 December 2021 and each winning team will be presented with a Mesothelioma UK winners certificate, signed by our CEO, Liz Darlison

Don't forget, Christmas doesn't stop for Covid so register your team now at www.mesothelioma.uk.com/event/meso-christmas-carol-off/

FUNDRAISING

The Power of Your Pledge – Legacy Week

By Jill Lemon, Senior Fundraiser, Legacy & Challenges Officer at Mesothelioma UK

If you believe, like us, that there should be a future without mesothelioma, then leaving a gift in your will can help us to continue that fight. It's our responsibility at Mesothelioma UK to raise awareness about the dangers of asbestos exposure, collaborating with like-minded people to get the message out there whilst supporting patients and their families through their mesothelioma journey. Putting patients first remains our key focus.

Sadly, mesothelioma will be around for a long while yet. Asbestos is in the fabric of our public buildings, schools, offices, hospitals and our homes, and asbestos doesn't care how old you are or what gender you are. If you are exposed, you are at risk. Therefore, we must carry on the fight against it and you can help us to do that.

You may have been seen by one of our specialist nurses, called our information line, received one of our information booklets, or accessed a travel grant enabling you to receive treatment. Leaving a gift in your will ensures that anyone diagnosed with mesothelioma will always have access to all of our services.

Gifts in wills are a vital source of income for all charities to help secure a future. They enable us to fund vital research into potentially life-saving treatments and maybe even a cure. They help to fund our team of mesothelioma clinical nurse specialists amongst many other things.

Leaving a gift in your will is not complicated. In fact, it's quite easy, especially as we provide a professional, free will writing service with all the guidance you need. This is available on our website for anyone to access at **www.mesothelioma.uk.com/leave-a-gift-in-your-will/**

If you're unsure or struggling in any way regarding writing your will, our free guide helps you get answers to any questions you may have. "What if my circumstances change?" "How do I start?" "How do I add a legacy to my existing will?". These questions and more are answered simply within the guide, as well as useful contact details to give you peace of mind if you have any further queries. **www.mesothelioma.uk.com/wills**

Legacy week begins here at Mesothelioma UK from 4-10 October, so there is no better time to begin thinking about leaving a gift in your will to help support Mesothelioma UK and make a real difference.

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

Our pledge as Mesothelioma UK is that your donation will help us to continue our vital work. From the smallest to the largest, every gift matters and will make such a difference. Most supporters leave a gift to our general funds so they can be used where they are most needed or there may be a specific area or project you would like to support, perhaps one personal and close to your heart. Any amount, no matter the size, is greatly appreciated and is a real honour. It reminds us of the continued commitment and generosity of our supporters.

It's your legacy, your choice.

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

If you want to know more, please contact us on 0800 169 2409.

Million Dreams Charity Ball

Solicitors Simpson Millar hosted a charity ball at The Edwardian, Manchester on 9 September 2021.

The event supported three causes – Mesothelioma UK, the Child Brain Injury Trust, and the Seashell Trust. The black-tie event included a three-course meal, drinks, auctions, raffles prizes, live music and much more, and aimed to raise as much as possible for their three chosen charities.

Move for Meso

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

Lottery

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

Vitality Big Half 2021

The Vitality Big Half took place on Sunday 22 August 2021 in London. It was amazing to see everyone out and running for charity again! Mesothelioma UK had 19 runners take part; Peter Barlow, Amanda Allison, Silvana Talbot, Jack Konda, Jessica Dobson, Sarah Wolstencroft, Tanya Garvin, Caroline Anderson, Pietro Saia, Claire Saia, Michelle Frogley, Anthony Barnett, Salli Shepherd, Katie Fisher, Anita Delaney, Andrea Flint, Graham Douglass, Rocky Marchant and our Mesothelioma UK CNS Simon Bolton.

Our fantastic participants have already raised over £13,000 (and still counting!) in support of Mesothelioma UK.

Keep an eye out on our website for news and updates about charity places for our 2022 challenges.

London Landmarks Half Marathon

On Sunday 1 August, the Mesothelioma UK team travelled to London to watch the first Marathon in the UK since lockdown began. We had 10 amazing runners take part in the race - Ellodie Stott, Phil Mighall, Jo Taylor, Ian Taylor, Clare Thornton, Allison Hanchett, Kit Garnett, Abigail Teague, Lauren Nunn and Danielle Martin.

Our runners did a fantastic job and have currently raised over £12,000 between them. If you would like to get involved next year, check out the 'Get Involved' section of our website or call the fundraising team on 0800 169 2409 and select option 2.

Team Meso UK do the Peak District Ultra Challenge

In July, Lorraine (Head of Nursing) and Liz (CEO) took part in the Peak District Ultra Challenge in support of Mesothelioma UK. They said "We are SO proud to be part of a pretty awesome team at Mesothelioma UK, all dedicated to doing everything and anything they can to support people living with mesothelioma. We have a vision that ensures every person diagnosed with mesothelioma in the UK has access to a locally based Mesothelioma Clinical Nurse Specialist.

"The charity currently supports 34 nurses doing just that, but we need at least another 5 or 6 to cover the whole of the UK. Each nurse we support costs the charity about £25k per year. If we are to achieve the vision before we both hang up our fob watch and uniform, we need to raise the money.

This could be the first of many Liz 'n' Lorraine fundraising adventures..."

Although the rain poured and they ended up windswept and wet through by the end of the trek, the team still completed it and raised a fantastic £1,829.34!

Brooke's sky dive for Mesothelioma UK

"I've done this fundraising skydive for my dad who was diagnosed with mesothelioma back in May last year during the first lockdown. With mesothelioma not being very well known, I wanted to share our story with friends and family to raise more awareness of the disease and was hoping to raise £1,000 for a brilliant charity. I was overwhelmed when I received over double that amount in donations. I'm so pleased I did it and had an awesome day while also helping a worthwhile cause."

Brooke raised an incredible £2,275 for Mesothelioma UK.

Colin's Summer Spine Race

On 1 June, Colin's father-in-law was diagnosed with mesothelioma. Colin's father-in-law worked in many places where he could have been exposed to asbestos. One area in which he did a lot of work was fitting medical gas lines in hospitals. In June 2021, Colin took part in the Summer Spine Race in support of his father-in-law.

"At the time, my focus was almost entirely on my upcoming race along the Pennine Way, easily the biggest challenge I have ever set myself. I decided to make it a little more meaningful by raising money for Mesothelioma UK."

Colin raised an amazing £1,380.85! Although he didn't have the easiest race, he has still pledged to take it all on again next year. You can read Colin's blog if you want to know more about his race!

www.theonlywayispennine.com

Tracey Bayliss – Dad's battle with mesothelioma

Roger was diagnosed with mesothelioma on 20 November 2020.

Tracey and Alix wanted to share their story about their dad and grandad, to remind others of the importance of gathering as much information as possible so that patients can make fully informed decisions about treatment options.

Roger was 80 years old but a young 80, full of energy. He was passionate about playing golf, walking, playing bowls, going on cruises with his wife Shirley, spending time in Spain with his friends, grandchildren and family. Dad also loved gardening growing his beans, attending to his hanging baskets and pots.

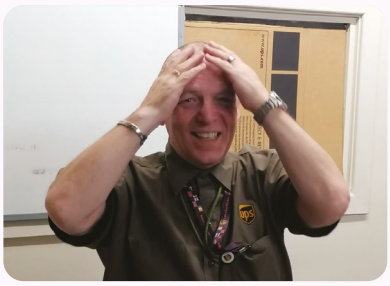
It was when he was in the garden with Mum when he felt tight chested, breathless and needed to sit down.

Due to Covid, Dad could not visit the GP so when Mum called to explain his symptoms, the doctor said it was probably a chest infection and prescribed Dad some antibiotics. After a week, Dad was feeling worse, the doctor just gave more antibiotics. Mum rang the doctors and got Dad admitted to hospital for an X-Ray/CT scan and biopsy. This showed results of Dad being diagnosed with mesothelioma and he was told that he had fluid on his lungs so then was fitted with a drain. When Dad was diagnosed with mesothelioma, he was all alone, Mum could not be with him. It must have been devastating news for him to hear. Doctors told Dad he had 18 months to two years, with this cancer.

It was only five months after being diagnosed with mesothelioma that we lost Dad. Roger will be sadly missed by his loving wife, children and grandchildren.

Tracey and her family have been fundraising in Roger's memory and have a raised a fantastic £2,371 in support of Mesothelioma UK.

Ian's Head Shave



My name is Ian Kennedy. I am 63 years old and I would like to tell you what led to me raising £1,200 for Mesothelioma UK.

You would consider having a full head of dark hair at my age a great bonus in life, but contrary to this fact, most of my peers at UPS would tease and joke about it calling me 'wiggy' etc. This was all done light heartedly but when someone suggested I shaved it all off, I saw the irony and thought it may be a great idea to do it for charity.

I jokingly said if people pledged over £1,000 I would do it. To my amazement my colleagues quickly pledged over £600 and I started to think seriously about which charity I would give the money to.

The charity that means most to me and my extended family had to be Mesothelioma UK. This is due to my father-in-law, Bernard Goulson being taken from us five years ago due to this terrible silent killer.

He was diagnosed initially with cancer in October and passed away on Boxing Day, when it was concluded that it was mesothelioma that had taken him so quickly and that he had probably had this in his system for many years.

Bernard was married to Barbara for over 60 years and spent his whole life working in the aerospace industry. He was one of 10 children in his family and knew great hardship growing up. As an intelligent man who had won a scholarship to Manchester Grammar School, he used all his energy throughout his life into helping 'the underdog' and worked tirelessly and often against common opinion to ensure that workers had good conditions and rights.

Bernard was a very calm and kind man who always loved younger people which led to the rest of the family getting involved and pledging generous amounts of money as it was their dad/grandad that had meant so much to them, and it felt like something positive to do.

Bernard would have done everything in his power to stop this condition afflicting the next generation. He inspired not only myself but also his son Neil and wife Hazel and their children Sam and Jess, along with his daughter (my wife) Linda and our children Sandi, Daniel and Adam. We thought the world of him and I am so proud to have been able to help do something positive in his name.

Christine's charity day for mesothelioma

We decided to do a charity day for mesothelioma because three of us lost our husbands with this horrible disease seven years ago. We met through going to mesothelioma meetings in York and stayed friends since.

I have a very nice local park near where I live, and three members of the bowling club offered to make the drinks (for free) and served the drinks all day. We had over 50 cakes and lots of fancy buns donated.

We did a leaflet drop in the area and put notices up in all the shops locally. The weather was kind to us, and we had a book stall and a tombola stall. It was a very successful and enjoyable day.

Christine raised an amazing £880 that she will split between Mesothelioma UK and the June Hancock Mesothelioma Research Fund.

Jack Lannigan's 24 hour live stream

So back in March this year, we as a family got the news everyone dreads to hear. My mum had been diagnosed with terminal mesothelioma, with it being that far developed that there was no chance of repelling it with any treatment.

It has been a difficult time for all of my family but one thing she has taught me since I was young, try and see the positives where they may not seem to exist. They're there, but they'll be difficult to see.

Since April, I have resumed a dream of mine to partake in the digital media world of Twitch, and this opportunity was provided to me by my mum with the promise I would make the biggest go of it I could.

The channel has been relatively successful, but now I am wanting to give back to the people that have been supporting my mum and others that suffer from this horrendous (and completely avoidable if hindsight was a superpower) disease. As such, on 26 June I hosted a 24 hour live stream on my channel with agreements made between myself, Mesothelioma UK and JustGiving to allow for all donations to go towards the charity.

Jack's 24-hour gaming live stream raised an incredible £1,307.27 in support of Mesothelioma UK. If you would like to get involved in online gaming for Mesothelioma UK, please get in touch with our fundraising team on 0800 169 2409 or email us at info@mesothelioma.uk.com

Ella walks 100 miles for Mesothelioma UK

My name is Ella Thompson, I am 20 years old. This is my fundraising story for Mesothelioma UK.

Over the past year I have started to really notice that not many people know what mesothelioma is and how it completely destroys families, just like it did mine.

On 8 August 2008, my family was ripped apart at the passing of Glyn Bates at the young age of 58. Glyn was the best husband, father and the most amazing grandad anyone could've wished for. Glyn is missed so much every day as he was such a funny, kind-hearted man.

Being Glyn's oldest grandchild, I always wanted to raise money and awareness of this rare form of cancer to as many people as possible. I wanted to make a difference in any way I could and at the same time, make my Grandad proud.

Over the month of June 2021, I completed 100 miles of walking in whatever weather conditions were thrown at me. As I live in the heart of the Peak District, I have such a wide range of gorgeous places to walk which made this fundraiser exciting for me. This was a big challenge, but was one of the most rewarding, amazing and proudest months of my life.

I created a JustGiving page which I shared on Facebook to raise money and awareness, and updated it so everyone could follow my journey to reach 100 miles.

At the end of June, I managed to raise a massive £670. I am so grateful for all the support from everyone. Lots of people donated in cash and many used the JustGiving page to show their support. I really hope this money will be used to help support all families who have been affected by this rare and aggressive cancer. I also hope this money can be used to help with research needed to find effective treatments and provide care for all who are effected.

I want to thank everyone who supported me and to those who contributed to this fundraiser.

I hope I've made you proud, Grandad. We all love and miss you so much.

20 for 20

The #20for20 campaign is back in September!

Mesothelioma UK and 19 other charities have come together to raise money for, and awareness of, rarer cancers and how important early diagnosis is.

The idea of the 20 for 20 challenge is to do something involving the number 20 – it can be 20 sit ups a day for 20 days, running every day for 20 days, baking 20 cakes, doing 20 minutes of swimming, reading 20 books – the choice is yours!

Last year our supporters raised a fantastic £2,232

and with your support we can really make a different to those diagnosed with mesothelioma.

Sign up at www.20for20.org.uk and each entrant will receive a Mesothelioma UK cap and t-shirt. Keep an eye on our social media and website for more details.

Newmarket Angling Club

24 July 2021 was a date to be remembered. It was the inauguration date for the first 'Bobby Coulson' memorial fishing match with £800 being raised for the Mesothelioma UK charity.

Bobby was a well-known angler in the Cambridgeshire area and following his untimely death from mesothelioma, his wife Jackie asked for a memorial fishing match to be arranged each year to raise money for Mesothelioma UK.

The match, with 14 Newmarket AC anglers and 14 'Jolly Boys Match Group' anglers, took place on Mark's lake and Emily's lake - at Frasers Fishery in Little Downham. It was a close match with a win for the Jolly Boys Match Group, with 100 points to Newmarket AC's 110 points. The overall winner was Newmarket AC's Dave Priestly.

Newmarket AC would like to thank the following:

- Jackie Coulson and family for the memorial shield and amazing food spread
- Fraser Gilbert for the use of the fishery
- Hooked Tackle, Alex Bates tackle and all individuals that donated prizes for the raffle
- Tracey Hawkes and Andy Hawkes for running the raffle
- The 28 anglers who fished the match with happy banter and a good competitive spirit

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

September
Run/Cycle/Sport for Charity Challenge Series 2021/22– events throughout the UK.
www.runforcharity.com/running-events/calendar
www.sportforcharity.com/activities/calendar

20 for 20 challenge
www.20for20.org.uk

25 September
Chiltern 50 Challenge
www.ultrachallenge.com/chiltern-50/

27 September
Mesothelioma PhD Scholars Showcase Webinar
www.eventbrite.co.uk

5 October
Facebook Live Q&A
www.facebook.com/therealmesouk

1-31 October
Go Sober in October
www.mesothelioma.uk.com

7-11 October
Saharan Challenge
www.ultrachallenge.com/the-saharan-challenge/

1 October
Annual Patient & Carer Day virtual conference
www.mesothelioma.uk.com/patient-carer-day/

4-10 October
Legacy Week/Free wills event
https://www.mesothelioma.uk.com/leave-a-gift-in-your-will/

28 October
Facebook Live Halloween Quiz
www.facebook.com/therealmesouk

30 October
Halloween Walk
www.ultrachallenge.com/halloween-walk/

1-30 November
Grow a Mo
https://www.mesothelioma.uk.com/grow-a-mo/

1 November
Meso Christmas Carol Off sign up opens
wwww.mesothelioma.uk.com

2 November
Facebook Live Q&A
www.facebook.com/therealmesouk

7 December
Facebook Live Q&A
www.facebook.com/therealmesouk

16 December
Facebook Live Christmas Quiz
www.facebook.com/therealmesoukm

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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