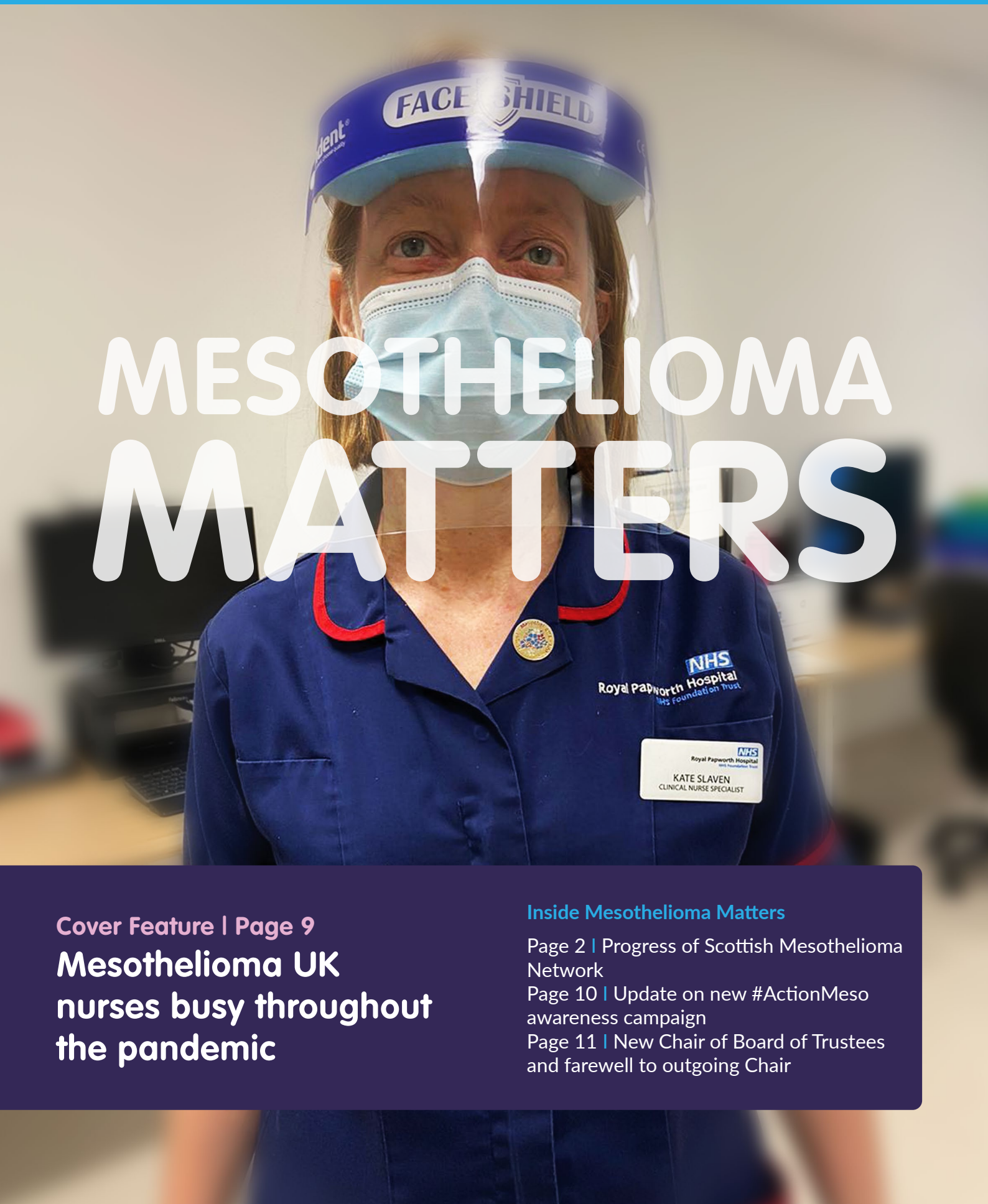
Spring Edition 2021

MESOTHELIOMA UK



MESOTHELIOMA MATTERS

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Mesothelioma UK nurses busy throughout the pandemic

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Transforming diagnosis and treatment for Scottish patients

The Scottish Mesothelioma Network (SMN) was established in April 2019 and comprises a team of clinicians from across Scotland dedicated to transforming diagnosis and treatment for mesothelioma patients. The team collaborates to share best practice and provide high quality clinical care, information and support to all patients, wherever they live in Scotland. The SMN also ensures that all patients have equitable access to potentially life-changing clinical trials and new treatment developments.

Macmillan Cancer Support and Mesothelioma UK have worked with local NHS boards across Scotland to pump-prime and deliver this service for the last two years, which optimises care and support provided to people affected by mesothelioma. Scotland has some of the highest incidence of mesothelioma in the world – a legacy of the country's industrial past and use of asbestos - so the service is having a great impact.

The SMN provides patients with a dedicated Mesothelioma Clinical Nurse Specialist (CNS) funded by Mesothelioma UK, who provides enhanced support in each region for patients and carers. Patients also have a dedicated Mesothelioma Lead Clinician to optimise clinical care and access to clinical trials.

SMN teams, based in Glasgow, Edinburgh, Inverness, Dundee and Aberdeen join a weekly virtual Multi-Disciplinary Team (MDT) meeting to represent the patients and feedback clear, high-quality management plans and clinical trial information to local teams. This approach aims to speed up diagnosis and treatment of patients wherever they live and to ensure that optimal care is delivered as close to home as possible.

Kevin Blyth, Professor of Respiratory Medicine, SMN Founder and Director, comments: "The service provides a weekly forum for clinical teams from across Scotland to share expertise, develop high quality care plans and provide increased access to potentially life-changing clinical trials to patients, wherever they live in the country. It also means that all Scottish patients with mesothelioma now get access to a dedicated Mesothelioma Clinical Nurse Specialist and dedicated pathways developed by Mesothelioma Lead Clinicians in each region.

"The network was launched in parallel with Mesothelioma Quality Performance Indicators. The SMN gathers mesothelioma-specific patient information which will be used to audit the care provided so that continuous improvements can be made with the aim of speeding up diagnosis as well as improving outcomes and the quality of life of our patients.

"Since launching the MDT in April 2019, we have had over 500 referrals to the weekly MDT meeting from over 25 hospitals across Scotland. In 2019, clinical trials including MARS2, CONFIRM, ATOMIC-Meso, INFINITE, SYSTEMS2, TRIZELL and MESO-Trap were recommended in 46 per cent of patients."

The SMN has launched a website packed full of information for patients and professionals at www.scottishmesotheliomanetwork.scot.nhs.uk

There is also a virtual support group on the first Friday of every month in partnership with Maggie's Inverness which the SMN CNSs attend. The group is attended by patients and carers from across Scotland and topics covered include benefits and support, information for carers, peer support, as well as information on treatments, trials and new developments. Please call Eilidh at Maggie's on 01463 706 306 or email highlands@maggiescentres.org

First Scottish Virtual Patient and Carer Event

The Scottish Mesothelioma Network will be holding its first ever Virtual Patient and Carer Event on 29 April 2021. There will be presentations from:

- Patients on their experience
- Clinicians on new developments including immunotherapy
- Latest research on gender in mesothelioma
- Support services on carer support and benefits
- Lawyers on legal and compensation issues
- Patient involvement opportunities
- Breakout sessions on managing breathlessness, fatigue and mindfulness, pilates
- Action Meso Day 2021

Tickets are free and for anyone involved in the global mesothelioma community including patients and carers, clinicians, support services, lawyers, health and safety experts, researchers, advocates, politicians, administrators and trials managers.

www.eventbrite.co.uk/e/scottish-mesothelioma-network-patientcarers-virtual-event-29-april-21-tickets-139925431733

Update on Project Wales

Mesothelioma UK's Project Wales is a two-year project to analyse patient needs and develop services across Wales. The aim is to ensure that all patients receive the standard of care outlined by the British Thoracic Society and recommended by the UK Mesothelioma Alliance; and to enhance mesothelioma services across Wales based on the latest research, studies, clinical trials, treatments and evidence in practice.

As a rare cancer with its own unique pathway, a diagnosis of mesothelioma is critical to:

- access appropriate services such as support groups, advice and information
- allow for a timely and relevant pathway including access to treatments, clinical trials and palliative care
- access the benefits and financial compensation due to patients.

An effective pathway is even more critical in light of the coronavirus pandemic. Patients are presenting later for diagnosis, pathways are having to be maintained, despite social distancing and all services are under unprecedented strain.

Sarah Morgan with Dawn Bowden AM, Member of the Senedd for Merthyr Tydfil and Rhymney, Chair of the Cross-Party Group on Asbestos'

Despite these significant challenges, the pandemic also presents a unique opportunity. Wales has historically been disadvantaged by normal face-to-face pathway processes due to its rural nature, with long distances for patients to access services, limited infrastructure and difficulty recruiting local specialists. The pandemic has forced a change towards remote working and this shift could represent a huge advantage for Wales.

By developing a 'hub and spoke' network of services across Wales, we will be able to provide equitable access to a wealth of specialist expertise and knowledge. This network will feed into existing services to support both patients and healthcare professionals.

Four months in, we have had an amazing response to the project with engagement from all across Wales. The first phase of the project has focused on gathering data and information, launching the project, and engaging interested professionals and services.

Selected highlights include:

- Initial project 'kick-off' meetings held in preparation for the first Steering Group meeting in March
- Funding secured for two new adopted CNS posts
- Local Lung MDT audit completed for all ten MDTs across Wales
- Distributing information regarding the latest research and treatments
- An increase in patient referrals for professional advice, information and support
- Setting up a virtual patient support group in partnership with AASC, now held monthly on the fourth Tuesday of each month (CafeAASC)
- Meeting with the ARCH Innovation Forum regarding research options
- Engagement with Welsh Cancer Network regarding project support
- Meeting scheduled in February with the Welsh Assembly Government

The need for a co-ordinated approach to specialist services for mesothelioma patients in Wales has never been more urgent. Mesothelioma UK Project Wales is well underway with the Steering Group meeting to initiate the second phase of the project.

Thanks to Pat Stone Meso Support

As a charity, Mesothelioma UK is extremely grateful for any funding that we receive. Over the years, we have built strong relationships with many organisations and among those is Pat Stone Meso Support.

Graham Pound set up the charitable trust in his wife's memory (Pat Stone). Pat was a science teacher at an inner London senior school for over 16 years up to 1988 and taught in the labs where asbestos mats and gauze were used extensively. She was diagnosed with mesothelioma in December 2013 and died the following November.

Together with four of her close friends, a charity was formed in Pat's name with a view to providing support and advice to patients and their carers diagnosed with this disease. This charity was funded by the monies received in lieu of court action to be taken on Pat's behalf.

Graham Pound said: "Despite Pat being a physics teacher in a large senior school, neither of us could recall hearing the term mesothelioma until she was diagnosed with this cancer around Christmas 2013. We had, of course, heard of asbestosis and its connection with exposure to asbestos but unfortunately, we quickly learned the difference in its prognosis.

"When Pat died some 11 months later, several of her friends and I wanted to try and do something constructive in her memory. Being deemed an industrial disease, we were able to successfully claim financial damages and with the settlement, used it in an effort to help increase awareness, research and support to those unfortunate enough to receive the same diagnosis as my wife. It was then that we came in contact with Liz Darlison and her dedicated team at Mesothelioma UK."

Mesothelioma UK is so grateful for the total funding of £104,000 received from the Trust. The monies have supported several projects including the appointment of a mesothelioma clinical nurse specialist in London, an innovative research project into non-invasive diagnosis, a study into how people can 'live well' with mesothelioma and the Mesothelioma Organisational Audit.

Mesothelioma Matters webinars

Our second Mesothelioma Matters webinar in January 2021 looked at mesothelioma surgery. We were fortunate to have John Edwards, Consultant Thoracic Surgeon from Sheffield Teaching Hospitals as our guest speaker. John gave a great presentation on Extended Pleurectomy Decortication (EPD), explaining what the procedure is, why it became the focus of such a large-scale clinical trial, why evidence to support the procedure, or not, is necessary, and if or how EPD can be accessed, whilst MARS 2 results become available.

The following webinars are planned for the next few months:

29 March 2021 - Chemo-Immunotherapy in Mesothelioma
Expert: Anna Nowak, Professor of Medicine, University of Western Australia, Director, Australian National Centre for Asbestos

26 April 2021 - The UK Peritoneal Mesothelioma MDT
Experts: Faheez Mohamed, Consultant Colorectal Surgeon at Basingstoke with particular interest in research into peritoneal surface malignancy and Samantha Westbrook, Mesothelioma UK Peritoneal Clinical Specialist Nurse

24 May 2021 - Mesothelioma Heterogeniety
Experts: Didier Jean, Senior Research Scientist at French National Institute of Health & Medical Research with particular interest in research into mesothelioma

28 June 2021 - Research Prioritisation
Experts: Dr Clare Gardiner, Senior Research Fellow with a particular interest in palliative care and Professor Angela Tod, Professor of Older People and Care with many years conducting and applying patient experience research

You can find details of these webinars and how you can join at www.mesothelioma.uk.com/events/webinars

Do You C Us?

Cancer52, an alliance of nearly 100 organisations working to improve outcomes for patients with rare cancers, is launching a new campaign in partnership with Pfizer in early 2021.

The ambition of the campaign, called Do you C Us?, is to raise awareness of the challenges facing people living with rare and less common cancers and highlight the need for change to address them.

The campaign will amplify the collective voice of those living with rare and less common cancers and target policy makers, parliamentarians and the media.

The campaign will feature a combination of activities with the centrepiece being a virtual Parliamentary event held in spring 2021. The event will highlight to parliamentarians, policy makers and national media the key issues facing people living with rare and less common cancers, and the need for their voice to be heard and interests represented. Patient case studies will also play an important part in the campaign.

The patient voice and the issues that are most important to patients will be front and centre of the campaign. Keep an eye on Mesothelioma UK social media for more information.

Newly published research in mesothelioma

Compiled by the University Hospitals of Leicester (UHL) 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 to UHL clinical librarians!

New scientific research

Utility of Immunohistochemistry for MUC4 and GATA3 to Aid in the Distinction of Pleural Sarcomatoid Mesothelioma From Pulmonary Sarcomatoid Carcinoma.
Author(s): Terra, Simone B S P; Roden, Anja C; Aubry, Marie Christine; Yi, Eunhee S Joanne; Boland, Jennifer M
Source: Archives of pathology & laboratory medicine; Feb 2021; vol. 145 (no. 2); p. 208-213

Rucaparib in patients with BAP1-deficient or BRCA1-deficient mesothelioma (MiST1): an open-label, single-arm, phase 2a clinical trial.
Author(s): Fennell, Dean A; King, Amy; Mohammed, Seid; Branson, Amy; Brookes, Cassandra; Darlison, Liz; Dawson, Alan G; Gaba, Aarti; Hutka, Margaret; Morgan, Bruno; Nicholson, Adrian; Richards, Cathy; Wells-Jordan, Peter; Murphy, Gavin James; Thomas, Anne; MiST1 study group
Source: The Lancet. Respiratory medicine; Jan 2021

Recurrence of mesothelioma after a macroscopic complete resection procedure: is a second radical surgery justified?
Author(s): Elsayed, Hany Hasan; Hassaballa, Aly Sherif; Ahmed, Taha Aly; Sharkawy, Hazem Youssef
Source: Interactive cardiovascular and thoracic surgery; Jan 2021

Switch-maintenance gemcitabine after first-line chemotherapy in patients with malignant mesothelioma (NVALT19): an investigator-initiated, randomised, open-label, phase 2 trial.
Author(s): de Gooijer, Cornedine J; van der Noort, Vincent; Stigt, Jos A; Baas, Paul; Biesma, Bonne; Cornelissen, Robin; van Walree, Nico; van Heemst, Robbert C; Soud, Magdolen Youssef-El; Groen, Harry J M; den Brekel, Agnes J Staal-van; Buikhuisen, Wieneke A; Bootsma, Gerben P; Dammeijer, Floris; van Tinteren, Harm; Lalezari, Ferry; Aerts, Joachim G; Burgers, Jacobus A; NVALT19 study group
Source: The Lancet. Respiratory medicine; Jan 2021

Volumetric PET Response Assessment Outperforms Conventional Criteria in Patients Receiving High-Dose Pembrolizumab for Malignant Mesothelioma.
Author(s): Ferdinandus, Justin; Barbato, Francesco; Chodyla, Michal; Fendler, Wolfgang P; Kessler, Lukas; Pomykala, Kelsey L; Metzenmacher, Martin; Krefting, Frederik; Hager, Thomas; Umutlu, Lale; Herrmann, Ken; Christoph, Daniel C
Source: Journal of nuclear medicine : official publication, Society of Nuclear Medicine; Feb 2021; vol. 62 (no. 2); p. 191-194

Ponatinib is a potential therapeutic approach for malignant pleural mesothelioma.
Author(s): Yang, Yi-Wei; Marrufo, Angelica; Chase, Jillian; Woodard, Gavitt A; Jablons, David M; Lemjabbar-Alaoui, Hassan
Source: Experimental lung research; Feb 2021; vol. 47 (no. 1); p. 9-25

High-intensity statins are associated with improved clinical activity of PD-1 inhibitors in malignant pleural mesothelioma and advanced non-small cell lung cancer patients.
Author(s): Cantini, Luca; Pecci, Federica; Hurkmans, Daan P; Belderbos, Robert A; Lanese, Andrea; Copparoni, Cecilia; Aerts, Sophie; Cornelissen, Robin; Dumoulin, Daphne W; Fiordoliva, Ilaria; Rinaldi, Silvia; Aerts, Joachim G J V; Berardi, Rossana
Source: European journal of cancer (Oxford, England : 1990); Feb 2021; vol. 144 ; p. 41-48

First-line nivolumab plus ipilimumab in unresectable malignant pleural mesothelioma (CheckMate 743): a multicentre, randomised, open-label, phase 3 trial.
Author(s): Baas, Paul; Scherpereel, Arnaud; Nowak, Anna K; Fujimoto, Nobukazu; Peters, Solange; Tsao, Anne S; Mansfield, Aaron S; Popat, Sanjay; Jahan, Thierry; Antonia, Scott; Oulkhouir, Youssef; Bautista, Yolanda; Cornelissen, Robin; Greillier, Laurent; Grossi, Francesco; Kowalski, Dariusz; Rodríguez-Cid, Jerónimo; Aanur, Praveen; Oukessou, Abderrahim; Baudelet, Christine; Zalcman, Gérard
Source: Lancet (London, England); Jan 2021; vol. 397 (no. 10272); p. 375-386

Immune checkpoint inhibitors in mesothelioma: a turning point.
Author(s): Ceresoli, Giovanni Luca; Pasello, Giulia
Source: Lancet (London, England); Jan 2021; vol. 397 (no. 10272); p. 348-349

New and old treatments for malignant mesothelioma: not just immunotherapy.
Author(s): Nowak, Anna K
Source: The Lancet. Respiratory medicine; Jan 2021

Surgery for malignant pleural mesothelioma after radiotherapy (SMART): final results from a single-centre, phase 2 trial.
Author(s): Cho, B C John; Donahoe, Laura; Bradbury, Penelope A; Leighl, Natasha; Keshavjee, Shaf; Hope, Andrew; Pal, Prodipto; Cabanero, Michael; Czarnecka, Kasia; McRae, Karen; Tsao, Ming-Sound; de Perrot, Marc
Source: The Lancet. Oncology; Jan 2021

Qualitative studies and patient experience

Recommendations for improving follow-up care for patients with mesothelioma: a qualitative study comprising documentary analysis, interviews and consultation meetings.
Author(s): Henshall, Catherine; Davey, Zoe; Walthall, Helen; Ball, Hannah; Shahidi, Mitra; Park, John; Rahman, Najib
Source: BMJ open; Jan 2021; vol. 11 (no. 1); p. e040679
Available at BMJ open

Clinical prognostic factors in pleural mesothelioma: best supportive care and anti-tumor treatments in a real-life setting.
Author(s): Ringgaard Petersen, Thomas; Panou, Vasiliki; Meristoudis, Christos; Weinreich, Ulla Møller; Røe, Oluf Dimitri
Source: Acta oncologica (Stockholm, Sweden); Jan 2021 ; p. 1-7

Malignant Diffuse Mesothelioma in Women: A Study of 354 Cases.
Author(s): Schwartz, Arnold M; Henson, Donald E
Source: The American journal of surgical pathology; Feb 2021; vol. 45 (no. 2); p. 286-287

Guidelines

The 2019 ERS/ESTS/EACTS/ESTRO Guidelines on the Management of Patients With Malignant Pleural Mesothelioma.
Author(s): Gelzinis, Theresa A
Source: Journal of cardiothoracic and vascular anesthesia; Feb 2021; vol. 35 (no. 2); p. 378-388

SEOM clinical guidelines for the treatment of malignant pleural mesothelioma (2020).
Author(s): Nadal, E; Bosch-Barrera, J; Cedrés, S; Coves, J; García-Campelo, R; Guirado, M; López-Castro, R; Ortega, A L; Vicente, D; de Castro-Carpeño, J
Source: Clinical & translational oncology : official publication of the Federation of Spanish Oncology Societies and of the National Cancer Institute of Mexico; Feb 2021

Divided by an Ocean of Water but United in an Ocean of Uncertainty: A Transatlantic Review of Mesothelioma Surgery Guidelines.
Author(s): Waller, David A; Opitz, Isabelle; Bueno, Raphael; Van Schil, Paul; Cardillo, Giuseppe; Harpole, David; Adusumilli, Prasad S; De Perrot, Marc
Source: The Annals of thoracic surgery; Feb 2021; vol. 111 (no. 2); p. 386-389

Please contact your own clinical library or view the journal's web pages to seek access to the full publications.

UHL Clinical Librarian Service
"bringing you the evidence"

Providing a voice for mesothelioma patients

Mesothelioma UK is committed to giving mesothelioma patients across the UK a voice so they can be heard.

We're all aware of the impact that COVID-19 and its subsequent restrictions have had on cancer services and people affected by cancer. We also know that cancer charities have a critical role to play in shaping and influencing the national strategy for treatment and care of patients, going forwards.

With this key advocacy role in mind, Mesothelioma UK has recently joined forces with the leaders of other One Cancer Voice charities nationwide to write to Sir Simon Stevens, Chief Executive Officer of the NHS, outlining our concerns (and support for the NHS) with some suggestions on what more can be done, focusing on the role of the independent sector, clear communications for people affected by cancer and more.

Sir Simon Stevens

We've also recently written formally to Matt Hancock, Secretary of State for Health and Social Care for confirmation of the Government's approaches to delivering chemotherapy at home, funding for more research, and support for an asbestos awareness, removal and improved management campaign in specific public buildings.

We will publish details of any responses received, as appropriate, through our usual communication channels.

Liz Darlison, CEO of Mesothelioma UK said: "As a leading UK cancer charity, we have a duty to ensure that the voices of mesothelioma patients and their families are represented on a national level. Through collaborations with influential groups such as the One Cancer Voice and through our own efforts, we're trying to gain interest and commitment to address issues and concerns that will hopefully offer our patients, their families and carers greater confidence in how their treatment is being impacted by all of the ongoing changes."

The latest on new clinical trials app

You may remember in previous editions of Mesothelioma Matters that we have talked about the development of a new clinical trials app. Here, our App Project Lead and Mesothelioma UK Team Leader, Leah Taylor updates on the current status...

"We had become aware that our clinical trials pull-out section had become quite cumbersome because of its size and while this was great news for the number of trials available, we were aware that it was not very user friendly and not really something you could keep in your pocket!

"Early last year, we started working in earnest with a developer on this exciting project and then Covid-19 came along and sadly hampered our progress significantly. The good news is that this project is now back on track and progressing well.

"In the app, you will be able to see the trials available, where trials are located and even add them to your own personal favourites list so that you have the information ready to discuss with your clinical team. We will also include general information to help you understand more about clinical trials. A key feature of the app will be that we can keep the information current and update it with any changes as soon as we know about them.

"Please bear with us while we finish the development. We look forward to sharing it with you soon. Once the app is launched, it will be free to download onto Apple and Android smartphone devices."

Supporting the mesothelioma community in Barrow

Bob Pointer is 72 years old and is a Royal Navy veteran, having served for almost 15 years.

On leaving the Royal Navy in 1979, he and his wife Veronica settled in Barrow, his wife's home town, where he found employment in local industries including the shipyard for 19 years.

Following several years of enjoying a work life balance of semi-retirement after leaving his job at the shipyard, Bob has now been retired for the past seven years.

A career in the Royal Navy

Bob takes up the story: "When I joined the Royal Navy, it was either that or the dockyard and as my father was in the Royal Navy, I was in many ways directed along that path like many others living in the local area.

"On the first Monday of a New Year in 1965, I travelled to Plymouth, being met at the station to be taken across the Tamar to HMS Fisgard where I signed on as an Artificer Apprentice.

"I worked as an OEA (Ordnance Electrical Artificer), working across the board on electrical or weapon systems, including diving equipment. My first ship was the Bulwark and my last was the Ark Royal, the best being Tiger. I had a short spell on Churchill, which is how I met my wife.

"Whilst in the Royal Navy, I would also come to know those with their roots in Barrow. Waiting for the train to travel back off leave on a New Year's Day night, there was another couple on the platform, and the wife was distressed and in tears. Boarding the train, her husband explained that he was off to Northern Ireland, whilst I was off to Icelandic waters. Vast difference."

Back on civvy street

"Returning to civilian life in the summer of 1979, I would have to consider my future employment and five years later, ended up at the shipyard.

"In the workplace, there would be a WWII Burma campaign para, a Lancaster rear gunner, who today would have been diagnosed with PTSD, and there was one who had been injured on his landing craft in Normandy. Many years later, I would be asked to visit a Royal Engineer also present on the beaches, who required advice on his previous asbestos-related claim. He had not received adequate compensation."

Developing local asbestos support groups

"I was volunteered to take on the role of secretary of Barrow Trades Council in 2004 with asbestos being an issue in the town. This led to the creation of BARDS (Barrow Asbestos-Related Disease Support) in 2006. CLASAG (Cumbria & Lancashire Asbestos Support Advice Group) was launched in 2019. Following my decision to retire, I was asked to continue which I have until during the summer when I was advised to take a step back after my cancer diagnosis.

"BARDS would be asked for advice by service veterans, plus on occasion directly to me, sometimes from former colleagues of mine or from other sources.

"Failure to deliver the proper compensation was nothing new in Barrow, as I would soon learn.

"Over recent years, I have been made aware of the work that many service veterans carry out in their local communities. As was said to me, it's putting back into the community."

"Mesothelioma does not discriminate"

"I do not have an asbestos-related disease at the present time and a scan showed no conclusive proof regarding pleural plaques. However, I am currently undergoing chemotherapy for stomach cancer.

"What I have learnt is that mesothelioma does not discriminate between status or profession. It has affected those in the world of entertainment, be they a noted film star or record producer, or those private secretaries or PAs. Neither does it differentiate between those not in the public eye, be they a teacher where asbestos remains an issue or a factory employee.

"In the Armed Forces, it has no respect for rank or status, affecting many, as I have learnt in recent times. Some started out like me as an apprentice. Indeed, I was recently contacted by an ex-apprentice who had been diagnosed with mesothelioma who lives in the Furness area."

UKNAR targets 1,000 schools in 2021 with asbestos awareness and prevention campaign

UKNAR's first, inaugural year has created a solid platform of awareness of Asbestos SMART and our aim to build a UK National Asbestos Register. Our task in 2021 is now to take the high levels of interest and support for our social mission and turn them into action with duty holders across the UK. Sharing information to save lives with Asbestos SMART QR code technology needs to be an intrinsic part of the routine management of asbestos across the public estate. UKNAR's primary mission is to make this happen and so prevent hundreds of future victims.

In light of this, we are taking our key learnings from 2020 and setting our sights on 1,000 schools adopting Asbestos SMART in 2021. This is still only about 5 per cent of UK schools that contain asbestos but will better protect hundreds of thousands of pupils, staff and contractors. It should also make a huge difference in increasing levels of asbestos awareness in UK schools, where so many people remain vulnerable.

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

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

Supporting Your Recovery

Leaving hospital to return home is something to look forward to but some people find it a little daunting. That's where the volunteers from the Royal Voluntary Service can help. They can support you at home by helping with practical things like accompanying you to the shops or just being there for reassurance until you feel more confident.

When you return home, the volunteers can provide a pack of food essentials, a useful contact list and a home safety check. You can then work with them to make a plan of the sort of help you might need.

Find out more about the Royal Voluntary Service at www.royalvoluntaryservice.org.uk

APPG – influencing change in the corridors of power

By Shelly Asquith, Health and Safety Policy Officer, Trades Union Congress and Secretariat to the APPG

The All-Party Parliamentary Group (APPG) on Occupational Safety and Health meets several times per year and also hosts a sub-group which meets to discuss asbestos. The Group aims to provide a forum for interested Parliamentarians to discuss asbestos-related issues, be aware of current concerns, and do proactive work like sponsoring reports and research.

Like all APPGs, the Group enjoys cross-party support. The Chair is Ian Lavery MP; President is Lord Hunt of Wirral, Vice-Chair is Lord McKenzie of Luton and Secretary is Martin Doherty-Hughes. Several other Commons and Lords members regularly attend including Stephen Timms MP, Margaret Greenwood MP and Baroness Donaghy.

Over the last year, all meetings have taken place online, which has increased engagement and attendance. The Trades Union Council and the Asbestos Victims Support Group Forum provide support to the group.

In recent months, the Group has focused on issues experienced by asbestos victims accessing the Industrial Injuries Disablement Benefit. Due to delays in processing applications, concerns have arisen about individuals not being granted their full entitlement, due to the calculation factoring in the applicant's age at the time of assessment.

Representations have been made to the relevant Minister by members of the Group, requesting claimants have their payments backdated to the time of application.

The Group also enjoys active participation from stakeholders from trade unions, charities, solicitors, and campaign organisations. For example, the International Ban Asbestos Network (IBAN), has raised concerns at Group meetings about the sale of Johnson & Johnson talc-based baby powder, withdrawn from the US market following concerns about its links to ovarian cancer. This presentation resulted in the tabling of an Early Day Motion in Parliament.

This year, the Group is sponsoring research investigating the current presence of asbestos in public buildings. We already know that many schools and hospitals still contain the toxic substance, potentially putting thousands of people at risk every day. We are hoping to get a clearer picture of the true scale of this problem.

We also know that the number of people diagnosed with asbestos-related illnesses, including mesothelioma, is on the rise. We want to ensure that those who currently suffer the consequences of asbestos exposure are recognised and supported.

We also want to prevent future victims of asbestos and make work safe. By engaging those who can influence change in the corridors of power, the APPG aims to do just that.

View from Simon Bolton, Clinical Nurse Specialist

It's been an extremely busy couple of months since I re-joined the Mesothelioma UK nursing team in mid-November 2020.

I've moved from Harrogate & District Hospital to Calderdale & Huddersfield increasing the hours I work from 15 to 37.5 per week thanks to an increase in funding from the charity.

I managed to maintain the Mesothelioma Support Yorkshire (MESSY) group throughout my time away from Mesothelioma UK and had to move the meetings to virtual events using the video platform Zoom due to the COVID crisis. With dedicated time to focus on the group, we are now meeting every two weeks and have a guest speaker at least once a month.

It's a strange time to start a new job and impossible to get to see all the members of the MDTs across the region face to face in the midst of a pandemic. It's actually difficult getting access to my new colleagues locally. Thankfully I have an excellent relationship with the MDT lead clinicians and lead lung cancer nurses. I've been able to use the data from the National Mesothelioma Audit 2020 to share the current state of mesothelioma care and support across the region. I've presented this to the West Yorkshire and Harrogate Cancer Alliance team. Following on from that, I have been invited to delve deeper into the local data and present that at each of the region's NHS Trusts via MDT business and audit meetings.

The Mesothelioma UK Organisational Report 2019 which reviews the 17 UK dedicated mesothelioma MDTs is another rich source of data. The absence of a regional MDT in the area I cover is a striking feature within the report and is a lever I have used to make steps towards developing such a service. The intention is to eventually ensure all

mesothelioma cases are reviewed by a panel of mesothelioma experts who will provide feedback to the referring Trusts.

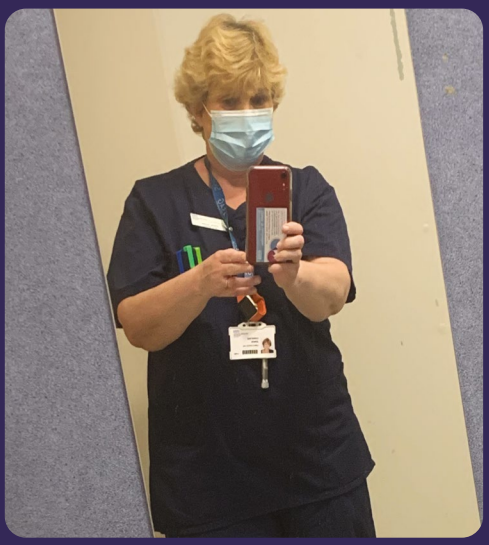
Communication is a big issue at the best of times but for teams working predominantly in a thoracic cancer, it's been tougher than ever, often being pulled in different directions to support the fight against COVID. With that in mind, I've devised a monthly update for the local teams. It provides latest news including links to recent publications and an invitation to the new Mesothelioma UK monthly webinar.

It's great to be part of the Mesothelioma UK family again. Hopefully it's clear that I'm kept busy across the region but I've always felt it's important to play a national role within the charity. I'm now back on the rota to handle enquiries coming into the Information Line. I've also had great fun hosting the Christmas and Valentine's Day quizzes.

Meso UK nurses busy at work

Throughout the pandemic and resulting lockdowns, our network of Mesothelioma UK nurses have been busy working, both in their usual roles with mesothelioma patients and where required, supporting other colleagues or departments in their respective hospitals and even in vaccination clinics.

We support all of their efforts!



ACTIONMESO

#ActionMeso launches new campaign called ‘Hard to Say, Easy to Prevent’

The ActionMeso team has launched a new public awareness campaign to raise awareness of mesothelioma and the dangers of asbestos.

As part of this campaign, the general public were invited to say the word ‘mesothelioma’. In reality, people who have never heard of the word have actually found it hard to say. The team are committed to raising awareness and sharing the message that this disease is easy to prevent if we take action today.

Please take a few moments to watch the ‘Hard to Say, Easy to Prevent’ video and social media activity, and support us by sharing the campaign and video as far and wide as possible. The campaign will be launched on actionmeso.org and through the ActionMeso social media channels and hashtag #ActionMeso.

#ActionMeso – share your selfies with us!

The Action Meso team aims to bring together the diverse mesothelioma community with a single voice. Through a number of campaigns, including our Selfie Board campaign, we want to reach out to patients, families, employers and the Government to make change happen today!

Please go to www.actionmeso.org/selfie-boards to download and share your photos.

Don’t miss out on #ActionMeso news and campaigns

The ActionMeso team don’t want you to miss out on our email newsletter, campaigns and our grand plans for Action Meso Day 2021. Please register your details at www.actionmeso.org

APPOINTMENTS

New Chair of Board of Trustees

Mesothelioma UK has appointed Professor Nick Maskell as its new Chair of the Board of Trustees. Professor Maskell is already a Trustee for the charity and will take up the role of Chair after Professor Mick Peake OBE stepped down.

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

For more on this story, visit our website at www.mesothelioma.uk.com/news/NickMaskell

Farewell to our outgoing Chair of Trustees

As we welcome our new Chair of Trustees, Professor Nick Maskell, we sadly must also bid a fond farewell to our outgoing Chair, Professor Mick Peake.

Professor Peake steps down from the board of Mesothelioma UK after a distinguished 17-year association with the charity, with many highlights including his award of an OBE (Officer of the Order of the British Empire) in Her Majesty The Queen's Birthday 2020 Honours List.

Mick explains: "I'm so proud of how the charity has evolved and how we've expanded over a relatively short period. The helpline continues to receive very positive feedback; our nurses, although small in number for a UK network, have increased the charity's profile and grown expertise for the mesothelioma community by becoming real patient advocates; a commitment to research has involved academics, doctors and clinicians; and more patients are getting to see top specialists sooner after receiving their diagnosis.

"I can't think of any group within the field of cancer where relationships between healthcare professionals and patients have been as broad – it's really unique.

"Mesothelioma UK has positioned itself as central to this 'community of care'. We've built up a really good team and they, with Liz's direction, have done the real work to achieve this. It wouldn't have worked without them."

Mick continues: "As for the future, my hopes for the charity are that we continue to make sure that every mesothelioma patient gets the best support and care available; that we can build up specialist MDTs; employ more nurses; raise awareness of the disease; look to work in partnership; and raise income to fund all of this.

"I personally want to thank all of the fantastic individuals who've supported us over the years, from local fundraising events up to large corporate donors. Indeed, a new national HQ has been secured, thanks to one of our great supporters.

"It's been very much a community effort; with patients, families and carers, nurses, researchers and consultants, other healthcare professionals, fundraisers, donors, stakeholders and partners all combining to create a community of care that didn't exist before."

For more on the story of Mick's involvement with the charity, visit our website at www.mesothelioma.uk.com/news/MickPeake

New mesothelioma nurse for Leicester and Leicestershire

Louise Nelson has been appointed as Mesothelioma UK's Clinical Nurse Specialist for the East Midlands and will be based at the University of Leicester Hospitals (UHL) NHS Trust. Louise will provide nursing care and support for mesothelioma patients being treated at UHL and link with colleagues across the East Midlands to promote equitable access to mesothelioma-specific support and treatment throughout the region.

The part-time Clinical Nurse Specialist position is funded by Mesothelioma UK. In her new role, Louise will focus on caring for patients with mesothelioma at every part of their treatment journey, helping to make their journey as smooth as possible.

She will provide specialist support and advice to patients, families, healthcare professionals, and link in with local patient support groups.

Mike Holmes joins Operations Team

Mesothelioma UK recently expanded its Operations Team by appointing a Senior Corporate Relations Officer. Mike brings significant experience in business development, in particular working in the asbestos-related diseases sector.

Mike's main responsibility in this new role will be to forge links and relationships with organisations which have an involvement with asbestos or asbestos diseases. This will include asbestos management companies, construction companies and health and safety organisations.

For more on this story, visit our website at www.mesothelioma.uk.com/news/MikeHolmes

RESEARCH

Supporting research

By Samantha Morgan, Senior Projects Manager at Mesothelioma UK

Mesothelioma UK is committed to spending the vast majority of its income on charitable activities. This includes our growing team of clinical nurse specialists, and funding innovative research and audit projects to improve the care of patients diagnosed with mesothelioma. Our aim is to spend one-third of our income on audit and research. We want to focus on supporting quality research and audit to improve treatment options, patient experiences, and care and outcomes for those affected by mesothelioma.

Our Research and Audit Scientific Committee (RASC) is responsible for overseeing all of Mesothelioma UK audit and research activity, and we are proud to be members of the Association of Medical Research Charities (AMRC), which helps to ensure that we fund the best research. The AMRC has assessed our research funding processes and regularly carries out a full audit.

Training and networking through the AMRC also helps maximise the impact of our research and fosters collaborations that deliver benefits to patients sooner. We are also members of the National Institute for Health Research (NIHR), which partners with health and social care charities to support high quality research. By working together with charities like Mesothelioma UK, the NIHR drives alignment in the health and care research ecosystem to ensure research provides the maximum benefit for patients and the public, and that resources and expertise are put to the best use.

In conclusion, we are well placed to support high-quality research, which we will share and disseminate widely to enhance patient care and experience.

Research grant award launched

In January, Mesothelioma UK launched two new research grants for 2021. Two funding streams are available, for up to £20,000 and up to £40,000. Applications must be received by **31 March 2021**.

Applications should detail a clinical research study aimed at evaluating the following interventions:

1. Improving the patient diagnostic pathway for mesothelioma
2. Improving symptom control mesothelioma
3. Improving the Quality of Life (QoL) in patients with mesothelioma
4. Evaluating an app or other technology for use in patients with mesothelioma

We are particularly keen to support projects that may lead to a larger application to Cancer Research UK (CRUK) or a National Institute of Health Research (NIHR) funding stream.

Studies are expected to be completed over a 1-2 year period, beginning December 2021.

Visit www.mesothelioma.uk.com to find out more.

Publication for mesothelioma research

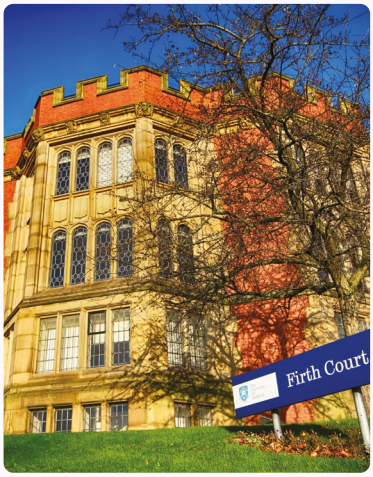
Dr Cathy Henshall, a Senior Nursing Research Fellow from Oxford Brookes University has been undertaking research into mesothelioma.

Her paper: *'Recommendations for improving follow-up care for patients with mesothelioma: a qualitative study comprising documentary analysis, interviews and consultation meetings'* has recently been published in the BMJ Open journals.

To read the full paper, please visit https://bmjopen.bmj.com/content/11/1/e040679

Mesothelioma UK Research Centre (MURC) update

The Mesothelioma UK Research Centre was officially launched on 20 November 2020 with the unveiling of our website and our Twitter account. Following on from the successful launch, we held our first Advisory Board Meeting via 'Google Meets' on 15 December.



Our Advisory Board comprises 21 research experts, clinicians, lawyers, asbestos support groups, and mesothelioma patients and carers who will advise us on our programme of research over the next three years.

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

Patient and Public Involvement (PPI) Panel
We are in the process of setting up a PPI Panel. Members will be people with a mesothelioma diagnosis or family carers and friends. The role of the PPI Panel is to provide advice and support to the research conducted by the Mesothelioma UK Research Centre in Sheffield but also to other mesothelioma research nationally and internationally.

If you are eligible and interested in being a member of the PPI Panel, please contact us to discuss this further, or have a look at the PPI section on our website: www.sheffield.ac.uk/murc/patient-and-public-involvement

Research Prioritisation Exercise (RPE)
In spring 2021, we will be starting a Research Prioritisation Exercise (RPE). The aim of the mesothelioma RPE is to identify unanswered questions about the mesothelioma patient and carer experience, and then to prioritise these areas through consultation with patients, carers and professionals, to identify research areas of most importance.

Further details about this will be circulated shortly.

Project update
Palliative care and the role of mesothelioma clinical nurse specialists
The aim of this study is to explore the palliative care needs of patients with mesothelioma, and explore the role of Mesothelioma UK clinical nurse specialists in providing care for patients with mesothelioma and their families. Data collection is now complete. Findings from the study will be available in summer 2021

Military Experience of Mesothelioma Study (MiMES)
This research is part of a larger project run by Mesothelioma UK that aims to improve the service and care provision to people who have served in the Armed Forces with mesothelioma.

The psychological effects of mesothelioma in the UK military context, the carers perspective
This PhD study, led by Virginia Sherborne, explores how carers of UK military veterans with mesothelioma experience the psychological effects of the disease. Virginia is currently recruiting participants for her interview study. Carers of UK military veterans with mesothelioma are eligible to be interviewed for the study. Please contact Virginia at hvsherborne1@sheffield.ac.uk if you are eligible and interested in taking part.

Experiences of mesothelioma during the COVID-19 pandemic
The MURC team have been working with Mesothelioma UK to analyse and publish the findings from the surveys conducted in 2020 on mesothelioma experiences and COVID-19. An article focusing on patient and family carer experiences has been accepted for publication and will be available later in 2021.

To contact the MURC, please email mesotheliomaresearchcentre@sheffield.ac.uk

LEGAL PANEL

Case shows importance of MAGS study research By Daniel Easton, Partner, Leigh Day

Mesothelioma Matters autumn edition reported on the MAGS study concerning healthcare workers affected by mesothelioma.

The study is a fascinating, insightful read about the sometimes difficult balance when healthcare workers become patients, and was funded by Mesothelioma UK and family and friends of Dr Mags Portman who died from mesothelioma in 2019.

I am a Solicitor specialising in asbestos claims and have represented many healthcare workers in asbestos cases. The publication of the MAGS study coincided with the settlement of a difficult mesothelioma claim in which I represented an inspiring Australian GP. Aged just 43 with two young children, Dr Kate Richmond was diagnosed with peritoneal mesothelioma as a result of asbestos exposure as a trainee and junior doctor at Walsgrave Hospital, Coventry from 1998 to 2004. The judge in charge described the case as exceptionally tragic "even by the standards of the asbestos (court) list". For me, the MAGS study closely reflected Dr Richmond's experience which highlights the importance of the research.

Dr Richmond expressed her desire to "raise awareness of the increasing number of hospital workers who are becoming ill due to exposure to asbestos at work."

The MAGS study goes a long way to addressing that awareness in an area which has seemingly been underreported in the past.

Dr Richmond described how workmen undertook maintenance on overhead pipes in basement tunnels and removed ceiling tiles on the wards as she walked past. A former worker described debris falling from the ceiling and that "we had to clean it up afterwards, so I just swept up the dust. The doctors and nurses walked past where we were working".

At a Court hearing in November, the Judge ruled there had been "serious and repeated failings" at the hospital. Despite policies in place at the time, he said the reality at the "coalface" was quite different and healthcare workers on the wards were exposed to significant quantities of asbestos.

The majority of compensation claims concern asbestos exposure many decades ago. Dr Richmond's exposure was incredibly recent, reflecting concerns in the MAGS study that the long latency period of mesothelioma means the true number of healthcare workers affected by asbestos exposure may not be known for many years and current statistics cannot accurately reflect the true level of the problem.

The MAGS study highlights the idea of 'three waves of asbestos disease' with the first wave being asbestos operations such as mining, the second from the use of asbestos products in construction, and the third being environmental exposure such as in hospitals and schools. The study notes that 'almost all NHS hospitals contain asbestos' and 'there is a concern that cases of mesothelioma in hospital could increase over time.'

Dr Richmond expressed concern for her former colleagues and in an interview with The Independent newspaper said: "I am far from unique, this is the tip of the iceberg. I strongly believe there is a hidden epidemic."

The MAGS study sought to provide up-to-date figures on the levels of mesothelioma amongst healthcare workers and makes it apparent that Office for National Statistics figures, which record just 177 deaths of NHS staff between 2002 and 2015, are 'not fit for purpose'. Even anecdotally this figure seems a vast underestimate, but the MAGS study provides proof of nearly 1,000 legal claims against the NHS for mesothelioma between 2004 and 2017. Given that many others will not have pursued a claim, the true figure is likely to be significantly higher and indicates a worrying level of mesothelioma among healthcare workers.

Interviewees in the MAGS study highlighted disappointment and even irony at developing an illness from their time dedicated to helping others. In an ITV interview, Dr Richmond described working up to 100 hours a week and felt "let down" by a hospital which "failed to protect me."

Among the study's recommendations, the most relevant to this article is the desire to raise awareness of the risks of asbestos with NHS staff and to introduce mandatory training.

Sadly, concerns about asbestos exposure cannot be dismissed as a thing of the past. The Independent reported 13 prosecutions of the NHS linked to asbestos since 2010 and a 'backlog of maintenance work in the NHS' with the need for 'a major investment programme.'

As we approached the final High Court trial in Dr Richmond's case, her experience was raised in Parliament with Lord Freyberg commenting: "If we cannot get it right in-house and have the NHS lead by example, how can we expect others to take steps to remove harmful materials from the workplace?"

Lawyers often look at the NHS from the outside. Having had the privilege of acting for an experienced NHS doctor, the MAGS study is a revelation on the impact of mesothelioma on healthcare workers.

There is little doubt that those who are now treated by dedicated NHS teams would be aghast at the thought of NHS staff running the same risks of asbestos exposure as they did years before. I truly hope the recommendations in the MAGS study are heeded and taken forwards so that future generations are protected and the same issues we tackle now are not repeated in years to come.

Rare point of law wins compensation for 61-year-old businessman who died from mesothelioma

Court of Appeal judges agree successful business would suffer following the death of its founder

By Peter Williams, Head of Asbestos Claims at Fieldfisher

In an extremely rare move, the Court of Appeal has overturned a decision by a High Court judge involving losses suffered by successful businessman, Mike Head after he was exposed to deadly asbestos in the 1970s.

A case for compensation against Mr Head's former employers, Culver Heating Ltd, was originally brought to court in 2019 by industrial disease legal expert Peter Williams at Fieldfisher. The claim included financial losses suffered by Mr Head once the mesothelioma prevented him from managing the profitable family-run heating and ventilation company he set up in 1987 after leaving Culver Heating.

Fieldfisher conducted his case on a 'hurry up' basis using the mesothelioma fast track in the High Court. Culver Heating admitted liability for exposing Mr Head to asbestos at the first hearing in 2019 and it was argued that, owing to his short life expectancy, Mike had lost more than £4 million of income during the years he was deprived of.

The High Court however disagreed and considered that Mr Head's business would continue to run even after his death and awarded only £175,000 in damages for other items, but no loss of earnings.

Peter described the idea pleaded by the defence and accepted by the Judge that Mr Head's earnings were somehow 'capital' rather than income and could be given away in his will as 'fanciful'.

Despite permission to appeal being refused, Peter would not give up and with Counsel from 12 Kings Bench Walk, challenged the ruling once again by citing a rarely used exception that the Appeal should be re-opened because of 'manifest injustice'.

Most such applications fail, but this one was granted, with Lord Justice Bean describing the case as 'perhaps the most striking one I have seen during six years' service in this Court'. Justice Bean said it was necessary to reopen the appeal 'in order to avoid real injustice'.

Justice Bean then overturned the earlier nil loss of earnings ruling and agreed with the claimant's original case that since Mike was the driving force behind the company and the profits he generated were a product of his own labour, he was entitled to full loss of earnings in the lost years, regardless of whether his company continued to generate profit after his death.

The case will now be readmitted to the High Court for re-evaluation of loss of earnings which will likely result in a seven-figure award to the family. Tragically, Mike died before the appeal was heard and will never knew that the original ruling was overturned and that his family will be well provided for.

Peter said: "The original judgment was devastating for Mike and his family. Our view was that the [High Court] Judge had made a serious mistake. I'm delighted that we finally proved this to be so and that it will now likely result in one of the highest mesothelioma awards.

"Mike's widow Debbie was adamant those suffering from mesothelioma would no longer be disadvantaged in claiming due compensation simply because they run their own successful businesses."

CLINICAL TRIALS

Immunotherapy improves survival for people with aggressive, asbestos-linked lung cancer

People with an aggressive form of lung cancer that's come back after treatment, leaving them with limited options, could live longer when treated with an immunotherapy currently available for several types of cancer.

The trial, funded by Cancer Research UK's Stand Up To Cancer campaign, found that the immunotherapy drug nivolumab increased survival and made the disease more stable for patients with relapsed mesothelioma when compared to those in the placebo group.

This is the first study to show that a treatment has been able to improve survival in patients with mesothelioma that's come back after chemotherapy.

The CONFIRM trial involved 332 people with mesothelioma from across the UK whose tumours were still growing despite being treated with standard chemotherapy and could not be removed with surgery. Two-thirds were randomised to take nivolumab once every fortnight, with the rest receiving a dummy drug.

People taking nivolumab lived on average for 9.2 months, compared to 6.6 months for those in the placebo group.

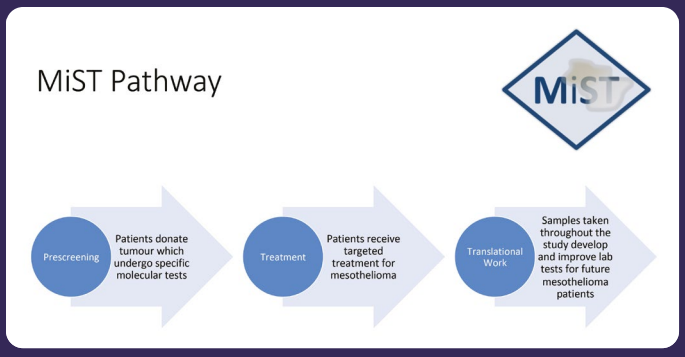
Patients who received nivolumab also had more stable disease. The risk of their cancer progressing was reduced by 39 per cent, with people not seeing their cancer worsening for three months compared with 1.8 months in the placebo group.

Nivolumab is already approved to treat some people with advanced kidney and non small lung cancers in the UK, as well as some advanced melanomas.

During the COVID-19 pandemic, NHS England endorsed nivolumab for some people with malignant mesothelioma as an alternative to chemotherapy, because it has less of a suppressive effect on the immune system and could reduce the risk of someone becoming seriously ill during the pandemic. This decision is currently in place until the end of March, but the data from the CONFIRM trial could help to make this option permanently available to patients.

For more on this story, please visit www.mesothelioma.uk.com/news/CONFIRM

Mesothelioma Stratified Therapy (MiST)



A stratified multi-arm phase IIa clinical trial to enable accelerated evaluation of targeted therapies for relapsed malignant mesothelioma

The aim of the MiST Trial is to find the identify personalised treatment pathways for relapsed mesothelioma patients, by identifying which patients are likely to get the greatest benefit from different types of drug therapies. Patients are asked for their permission to donate some of their tumour (their pathology block) to labs in Leicester, which will run specific tests on the tumour. Patients will then receive treatment in one of the treatment arms available. We are open at different sites in the UK, so you would receive treatment in the one closest to you.

We will take samples at different time point throughout the study: some of these will help develop lab tests to help for faster diagnosis of malignant mesothelioma much quicker, and they may also help us to establish the most appropriate therapies for an individual patient in the future. Genomic analysis on some of the samples can help us to understand why patients respond to the same treatment differently.

This trial is funded by the British Lung Foundation.

ARMED FORCES

Patient story - Karen Spence

Karen's husband, Mick, died of mesothelioma in 2020, very shortly after diagnosis. Karen shares their story in the hope that others will not be afraid to ask questions when faced with a similar situation.

Michael – or Mick as he was always known – joined the army at just 17 years old. He was a Royal Engineer and talented rugby player. Mick loved the army life and being a soldier was very important to him.

Mick met Karen in 2004. They enjoyed a whirlwind romance and Karen says they 'just knew they were soulmates'. The pair married just two years after meeting in December 2006.

Mick was diagnosed with mesothelioma in February 2020. When giving Mick and Karen the diagnosis, the consultant asked if Mick might have been exposed to asbestos in the past. This is when Mick said that it was quite likely that he was exposed during his time in the army – either through his work as an engineer or during the bombing of the barracks.

Not having heard of mesothelioma before, Karen researched it as she wanted to know as much as possible about his prognosis so that they could plan for the time he had left.

Despite the devastating diagnosis, when Karen talked to the medical team, they were able to discuss discharging Mick and it was thought that he had a few months to live.

Tragically, after a serious fall out of bed, Mick deteriorated quickly and with Karen by his side, died just two and a half weeks after his diagnosis.

The tragedy has taught Karen that anyone in a similar situation should never be afraid to ask questions and to keep asking. She feels that, for years, all of Mick's symptoms were put down to his TIAs and that nobody investigated any further. Karen wonders if, had they pushed for further investigations and asked more questions, the mesothelioma may have been found sooner.

Karen would encourage patients and carers to be aware of symptoms and to mention, as soon as possible, if there has been exposure to asbestos.

For more on this story, visit our website at www.mesothelioma.uk.com/news/KarenSpence

Mesothelioma UK celebrates Armed Forces Day 2021

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

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

Speakers will include Liz Darlison, Mesothelioma UK CEO and Mesothelioma UK Clinical Nurse Specialist, Anne Moylan.

Mesothelioma UK Armed Forces project shortlisted for 2020 HSJ Awards

Mesothelioma UK's 'Supporting our Armed Forces' project has been shortlisted for the Military and Civilian Health Partnership Award at the 2020 HSJ Awards, recognising an outstanding contribution to healthcare.

Mesothelioma UK has been shortlisted despite the tough competition from over 1,000 entries. The 'Supporting our Armed Forces' project has been selected based on 'the ambition, visionary spirit and the demonstrable positive impact that their project has had on patient and staff experiences within the healthcare sector'.

Winners will be selected ahead of the ceremony, which will take place virtually in March 2021.

For more on this story, visit www.mesothelioma.uk.com/news/HSJ2020

Study update - armed forces, mesothelioma and carers

Virginia Sherborne is currently conducting a research study at the Mesothelioma UK Research Centre at the University of Sheffield. Since September 2020 she has been interviewing the partners/carers of British military veterans with mesothelioma to find out about their experiences.

As a result of her interim findings, Virginia was recently able to make an evidence submission to the UK Parliament's Defence Committee Inquiry 'Women in the Armed Forces: from recruitment to civilian life'. Her evidence addressed one of the committee's areas of focus: whether the needs of female veterans are currently met by the available services.

Virginia is looking to recruit four more interviewees for her research study. Anyone interested in participating should get in touch through the Mesothelioma UK Information Line.

FUNDRAISING

A huge thank you from Mesothelioma UK

Just a little note of thanks to Cllr. Patrick Chung, West Suffolk Council and his team in Bury St Edmunds and Mrs Tina Borris of Lloretta da Luca Salon and her team in Warley, Essex for all of the effort they have put into raising a generous amount of funds, in the most difficult of circumstances and, some atrocious weather conditions.

In addition, Mesothelioma UK and Anglia Asbestos Disease Support Group CNS Nurses Fund and the Research Fund have also benefitted from fundraising activities and events respectively.

The East of England region have collected £6.7K in donations during the course of the pandemic year, January 2020 to 31 January 2021. Thank you to all of the volunteers and fundraisers.

Friends of Meso

If fundraising is not for you, why not become a Friend of Meso instead? Fundraising isn't always for everyone trying to balance home and work commitments, but by setting up a regular donation to Mesothelioma UK you can still be committed to the cause. For as little as £5 per month you can make a difference and help us to continue to support our patients and their carers.

By becoming a Friend of Meso you will receive early notification and access to tickets for all of our virtual and live events, such as the Ladies Lunch, the Awards Evening and the annual Patient & Carer Day.

As well as having exclusive access, when you sign up you will receive a pack of Forget-Me-Not seeds and a Forget-Me-Not pin to wear in support or in memory of those with mesothelioma. Finally, you will be kept up to date with our quarterly progress email.This will ensure you know what's going on in the mesothelioma community as it's happening.

Email info@mesothelioma.uk.com or call 0800 169 2409 for further information.

Matched Giving Scheme - philanthropy in the workplace

The Fundraiser
Give your fundraising donations a boost by asking your employer about the 'Matched Giving' or 'Matched Funding' Scheme.

Lots of employers are now offering this scheme to help support their employees while raising funds for causes that are close to their hearts.

They may match pound-for-pound what you have raised or they will have a specified amount up to which they will fund, boosting your total donations and giving you the feeling that your employer is supporting you and your cause.

When raising money for your chosen charity, let your employer know what you are doing and why you are doing it! You may be the reason for them to join this scheme as it has great benefits for them too.

The Employer
Being part of a Matched Giving Scheme is one of the best ways to engage with your employees. It shows you care about them and the environment in which you work, and will help motivate and boost morale among all employees by knowing they have your support.

It also helps to promote a culture of workplace giving, making a bigger impact to raise more for good causes. It also has a tax benefit too as contributions can be tax deductible.

If you would like further information, please contact Jill Lemon, Senior Fundraiser, Legacy & Challenges Officer at Mesothelioma UK on 0800 169 2409.

Calling all kiltwalkers!

There's an opportunity for our Scottish supporters to get involved in some local fundraising during the Kiltwalk challenge from 23-25 April 2021. Kiltwalks are mass participation walking events that raise much-needed funds for charities and projects with events taking place across Scotland - Glasgow, Aberdeen, Dundee and Edinburgh.

Kiltwalkers can raise funds for Mesothelioma UK and thanks to the generosity of Sir Tom Hunter and The Hunter Foundation, all funds raised will be topped up by 50 per cent.

thekiltwalk.co.uk/scotlandsvirtual

Online shop

We now sell a range of items in our online shop such as cotton tote/shopper bags, lapel pins, wrist bands and forget-me-not seeds. Please take a look at the range at www.mesothelioma.uk.com/shop – the tote bags are currently on sale at just £7!

Matt & Brian Cassidy take on Grow a Mo for Meso

My Dad, Brian was diagnosed with mesothelioma back in March 2020 just as the pandemic started. After the shock news and finding out who to turn to for help, my Dad got massive support from Mesothelioma UK after contacting them.

We found out that voluntary donations were a large part of their income, so we both decided to take part in Movember to raise money for the excellent advice and support they have been providing since his diagnosis.

And whilst my Dad can grow a pretty awesome moustache, I had to spend the month looking like a teenager with his first wisps of bum fluff! So, we'd like to say a big, big thank you to every one of our friends and family who donated to our Movember fundraising page. We've been absolutely overwhelmed by the response and donations received and with your help and generosity, we completely smashed our targets multiple times!

We even managed to make 'Top Fundraiser' on Just Giving as one of the most successful Movember fundraisers, putting us in the top 1 per cent of all campaigns!

In total, we raised £3,653!

We'd like to thank everyone at Mesothelioma UK for all the hard work they do and we're now looking forward to our next campaign!

Cheryl's virtual half marathon

Cheryl Hardy has been a Pleural Specialist Nurse at the Norfolk and Norwich Hospital for nearly three years, and decided that she wanted to do some fundraising in aid of Mesothelioma UK.

"I take part in running events every so often to try and improve my fitness levels. After a year of running a limited three miles twice a week, I decided to challenge myself to do a half marathon.

"I looked at local running events and always wanted to attend the 'Ely Run' events as I lived there previously and the city is lovely. Unfortunately, due to Covid it turned into a virtual event, but I took the opportunity to attempt this around my village where I currently live.

"I chose Mesothelioma UK to raise money for as it is so special and personal to my experiences as a Pleural Nurse Specialist. We are seeing a big increase in mesothelioma diagnosis in our pleural clinics and because of Covid, this has been causing added barriers for support. Mesothelioma UK provide vital support for the patients and families, it was an obvious choice to raise funds to aid this.

"I was able to run the half marathon on a very wet day with my daughter and partner cheering me on. I managed to raise £590 for mesothelioma and this is mainly from the amazing respiratory team's support. I will definitely continue my support for Mesothelioma UK and will enjoy coming up with different fundraising ideas."

Danielle's virtual hike in memory of Eric

Mesothelioma was something that my family and I had never heard of before January 2020 when my Grandad, Eric, was diagnosed.

At the age of 18 in 1956 he was drafted into the Royal Engineers and was deployed to Christmas Island and witnessed the nuclear testings. His regiment was transported to and from Christmas Island on a converted cruise ship that had asbestos lagged pipework in his living quarters. Grandad didn't talk about his military service as it upset him.

After many years he met the love of his life my Grandma, Barbara. Sixty-three years, three children, four granddaughters and one great grandson later, he was diagnosed with mesothelioma after two pleural effusions in a short space of time. Even after his diagnosis, Grandad was a true warrior and was never seen without a smile on his face until we sadly lost him in July 2020.

I work for a company called Cellular Solutions who are incredibly passionate about supporting charities that are close to our heart. I chose to support the charity that's closest to mine, Mesothelioma UK.

Amidst the pandemic, charities are facing a tsunami of need so we decided that amongst the chaos we wanted to do some good and take on Everest. Whilst abiding by lockdown laws and social distancing, we took to completing our altitude pledges using whatever means we had. Some of my colleagues climbed the stairs in their flats or house, used home treadmills or picked the steepest hill closest to their home. I am lucky enough to live a stone's throw from Beachy Head, so I hiked from Birling Gap to Beachy Head and back again on a cold and blustery day. I reached out to all my friends and family to support me with donations in climbing 2,000 ft towards our target of 29,031ft of Mount Everest. Two muddy falls and a torrential rainstorm later I made it! My total raised stands at £540 for Mesothelioma UK.

My Grandad was and is one of the most important, special and loved men in my life and I know that helping the vital work of Mesothelioma UK would have made him very proud. He would have said 'I taught you well!'.

Lizzy's Christmas cards for Mesothelioma UK

My sister-in-law was diagnosed with mesothelioma in 2019.

As any relation or friend of a sufferer knows, you feel a great need to do something to help in some way. Our family is spread far and wide across the country so, on a practical level and with the Covid outbreak, physically being there has sadly been an impossibility.

As an artist who sells privately and via the online shop Folksy, I decided to transform some work into Christmas and birthday cards, with a donation from each sale going to Mesothelioma UK. A small drop in a huge ocean but hopefully, lots of tiny voices will make one big shout to help the outcome for patients with such a challenging disease.

I'm looking forward to developing a wider range of cards and gifts to add to my Mesothelioma UK charity range. Maybe the forget-mesothelioma-not flower would be a good start?

On a happy note, my sister-in-law is doing fantastically well after surgery and treatment at Basingstoke Hospital – another incredible team of people.

Lizzy's Mesothelioma UK charity cards are available from her @wolf_and_bee Instagram page or at www.folksy.com/shops/wolfandbee

Joe's sponsored Paint by Numbers

"Trying to think of things to do while we are in a third national lockdown is getting harder. Especially when you have a 12-year-old son who just wants to game, so we thought we would raise some money for Mesothelioma UK who helped us during my dad's illness. I had hoped that we could have taken part in a fun run or something similar to raise money and awareness for mesothelioma.

"We were told my dad contracted mesothelioma as an apprentice 40 years ago due to breathing in asbestos. It laid dormant for all those years and it wasn't until he was 61 that the effects of the asbestos were found and the mesothelioma diagnosed.

"Eric was a plumber and for anyone that knew, he would eat sleep and breathe the job. Working was his life and he was heartbroken to have fallen ill because of the work he loved. He has a short and painful final prognosis but was still Eric the Viking until the end.

"I therefore tasked my son to raise money for Mesothelioma UK by undertaking a sponsored paint. It is a painting by numbers so anyone that has done these will know they are a labour of love and very fiddly. The painting took around 10 hours to complete and we may even raffle off the final product!"

Kelly's son Joe raised an amazing £326.25, including Gift Aid, in support of Mesothelioma UK.

Pilates for Mesothelioma UK

Julie Roberts, who is the owner and teacher at Ostara Pilates, opened a JustGiving Page to run a donation-based Pilates class with proceeds going to Mesothelioma UK.

"In 2015 I lost both my Dad and Uncle to mesothelioma within eight weeks of each other. Mesothelioma is a fatal form of cancer that affects the chest plura and respiratory system and is caused by exposure to asbestos. There is no cure for it.

In 2016, I started a national lobby campaign against the Scottish Government after discovering that the UK has the highest rate of mesothelioma in the world with the most concentrated rates in the West of Scotland, and yet it remains strangely missing from the Scottish Government's Cancer Strategy, is excluded from cancer waiting times and receives no central funding, meaning health boards have no incentive to improve outcomes for anyone diagnosed.

"I have worked in partnership with a number of charities and clinicians over the last four years to help raise the profile of mesothelioma in Scotland, which has given rise to the establishment of a network for the treatment of mesothelioma in Scotland spearheaded by Prof. Kevin Blyth, a leading respiratory consultant at the Queen Elizabeth Hospital in Glasgow. I sit in this network as a patient and carer representative.

"This network would not be possible without vital funds provided by Mesothelioma UK, which is why I have chosen them as the charity for this workshop.

"A heartfelt thanks to Jo Hatherley of The Vital Breath, for waving her fee for this workshop and making this donation possible."

Julie's donation-based class raised a fantastic £412! For more information on Julie's unique online pilates membership, The Lifetonic Club, visit ostaralivingonline.com/join-the-lifetonic-club/

Mesothelioma UK Lottery

Mesothelioma UK has launched a lottery! Have you got your tickets yet? There are amazing prizes to be won like a jackpot draw of £2,500! Tickets are £1 per week and 50 per cent of the ticket cost goes to help us continue our work and the more tickets bought, the bigger the cash prizes are. The draw takes place every Saturday. Get your tickets at www.onelottery.co.uk/support/mesothelioma-uk

Dean Collins runs for Mesothelioma UK

"I have been doing runs for charity every year since 2006 right up until 2020 when the usual runs I take part in were cancelled. I've raised funds for lots of great causes over the years, children's hospices and cancer charities too, one of which we are always grateful for having helped my niece through both her cancer treatments when she was younger. I was pleased to find out that Run For All the Jane Tomlinson Charity was planning to allow people to do a virtual run over Christmas 2020 and use it to raise funds for their individual charities.

"I have to be honest I'd never heard of mesothelioma before until my father in-law was struck down with it a couple of years ago. It's had a devastating effect on him. He has been a professional footballer in the past and after retirement went into industry to keep a wage coming in for his family. That's where he was exposed without knowing that years later it would come back to cause such a terrible outcome.

"It was during his initial chemo treatments that we got to meet other people who'd also been just as unfortunate, and I've heard a lot of their terrible stories too. It affects people from all walks of life. It was also at that time where we heard about your charity too.

"I had intended to run for Mesothelioma UK during the York 10k in the summer of 2020, but this was obviously cancelled. When I heard about the Run For All Jog, I thought it would be a perfect chance to get the sponsorship I'd missed out on. All my friends and family were happy to donate too, even got some surprise ones from people. So, I ran my 10k on 29 December in the early evening as the sun was setting. It was a strange feeling even though I run that route three times per week I felt connected to an event, even though I didn't have the usual crowds cheering, only the occasional dog walker.

"My wife took my photograph just before I set off. I had to run in my Mesothelioma UK colours which you'd kindly supplied."

Dean raised an amazing £291.25 for Mesothelioma UK!

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

HSJ Award
17 March 2021
www.awards.hsj.co.uk/hsj-awards-virtual-attendee-registration

Chemo-Immunotherapy in Mesothelioma Webinar
21 March 2021
www.mesothelioma.uk.com/events/webinars

19th BTOG Annual Conference (virtual)
22 and 23 April 2021
www.btogwebinars.org

The UK Peritoneal Mesothelioma MDT Webinar
26 April 2021
www.mesothelioma.uk.com/events/webinars

Scottish Mesothelioma Network Patient and Carer event
29 April 2021
www.eventbrite.co.uk/e/scottish-mesothelioma-network-patientcarers-virtual-event-29-april-21-tickets-139925431733

Muffins for Meso fundraising campaign
1-31 May 2021
www.mesothelioma.uk.com/getting-involved/fundraising

International Mesothelioma Interest Group Virtual Conference
7-9 May 2021
https://imig.org/

Ultrachallenge Jurassic Coast
22-23 May 2021
https://ultrachallenge.com/jurassic-coast-challenge

Mesothelioma Heterogeneity Webinar
24 May 2021
https://www.mesothelioma.uk.com/events/webinars

Ultrachallenge London2Brighton
29-30 May 2021
https://ultrachallenge.com/london-2-brighton-challenge

Miles for Meso
1 June-30 September 2021
www.mesothelioma.uk.com/getting-involved/fundraising

Ultrachallenge London Summer Walk
5 June 2021
https://ultrachallenge.com/london-summer-walk/

London Landmarks Half Marathon
1 August 2021
www.llhm.co.uk/

London Vitality Big Half Marathon
22 August 2021
www.mesothelioma.uk.com/fundraisers/vitality-big-ha

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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