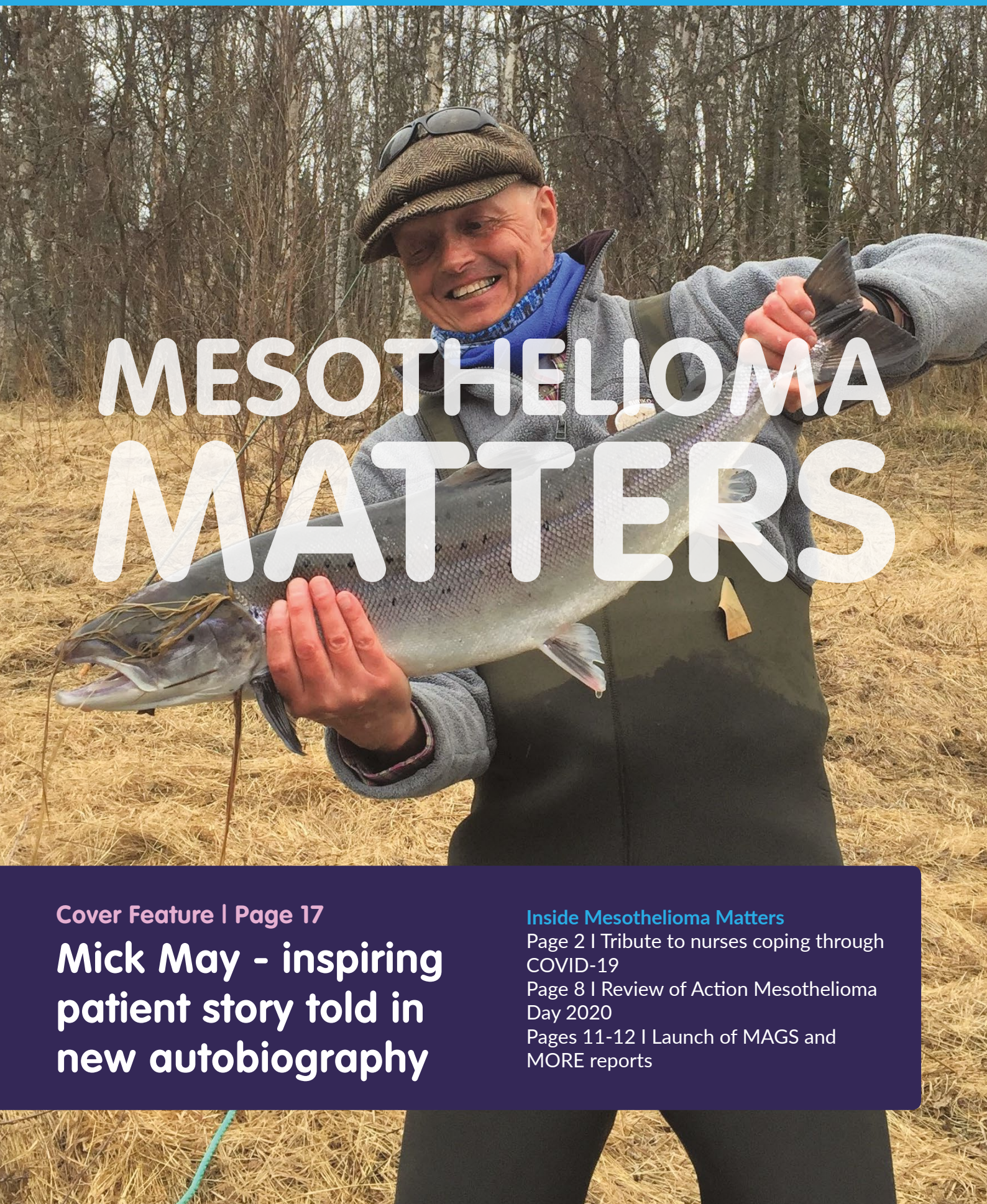
Autumn Edition 2020

MESOTHELIOMA UK



MESOTHELIOMA MATTERS

Cover Feature | Page 17

Mick May - inspiring patient story told in new autobiography

Inside Mesothelioma Matters

Page 2 I Tribute to nurses coping through COVID-19
Page 8 I Review of Action Mesothelioma Day 2020
Pages 11-12 I Launch of MAGS and MORE reports

Nurses COVID-19 tribute

By Lorraine Creech, Head of Nursing at Mesothelioma UK

There can be no doubt that COVID-19 has changed the mesothelioma community with the impact it has had on patients, families, our Operational Team, the Clinical Nurse Specialist Team and the NHS, as a whole. The virus has selected some of our kindest and most worthy citizens as casualties as treatment has been delayed or paused, and clinical trials were halted.

The pandemic has caused many NHS Trust management systems to turn upside down as healthcare professionals adapted to different roles from their traditional qualification. Some policymaking and processes of command were initially put aside a little, providing frontline colleagues with the flexibility needed in a crisis to make services run safely and swiftly.

It appeared that healthcare professionals mattered much more and because they were given trust and respect, some alternative care and support pathways were quickly put into action. Although very testing and scary at times, achieving solutions to problems led to job satisfaction for our Mesothelioma UK Clinical Nurse Specialists.

Along with social carers, teachers, NHS staff and all other key workers, our Mesothelioma UK Clinical Nurse Specialists have done an amazing job using their initiative to get things done. Some were redeployed to intensive care units, hospital wards and palliative care teams and settings. I am extremely proud of our Clinical Nurse Specialists for often stepping out of their comfort zones and rapidly being trained up in new skills or some that they had not undertaken for a long time.

Our mesothelioma patients, carers and families are always foremost in our minds when providing care, information and support. In addition, I found it amazing to see how our nurses supported each other by linking up in WhatsApp chat rooms, etc, and showing each other random acts of kindness which occurred because each one had some experience of what others were going through.

Having the freedom to use their initiative and being treated with humanity and generosity worked so well, and particularly helped those working on the frontline. It has been challenging and at times overwhelming, but they have been so adaptable. Many were concerned about their family and loved ones, not being at home enough or the fear that they could bring the virus home.

The psychological effects have been huge for everyone. The recent Cancer52 Patient Survey (July 2020) showed that cancer patients were as concerned about COVID-19 as they were about their cancer. The Mesothelioma UK Clinical Nurse Specialists recognised this and tried to offer support and information to patients as they became concerned about both life-threatening conditions.

Going forward, I think that we will need to be aware of the emotional impact this has had on our nurses and this will require careful monitoring. However, their compassion, commitment and dedication remains resolute and I have the utmost pride and admiration for them.

Professor Mick Peake added: "As the Chair of the Board of Trustees at Mesothelioma UK, I would like, on behalf of the Board, to thank all of our staff in the Operational Team, Nursing Team and other project workers for their fortitude and skill in navigating Mesothelioma UK through the difficult times of the coronavirus pandemic so far. The trust that staff have placed in each other and the importance of teamworking has created an ethos to help us serve patients, carers and the mesothelioma community as a whole, in the best way possible."

COVID in the Peninsula

By Mesothelioma UK Clinical Nurse Specialist, Christine Jones

When the bells struck at midnight on the 31 Dec 2019, a New Year and new hope was ushered in. Those of us lucky enough to be able to attend were looking forward to the annual pilgrimage to Dublin in late January and the British Thoracic Oncology Group (BTOG) conference, knowing that we also had the International Mesothelioma Interest Group (IMIG) meeting in March in Brisbane, along with Mesothelioma UK's Ladies' Lunch in Manchester.

The beginning of the year heralded a very full diary with lots of updates on the horizon and whilst we were aware of the news from China of a new virus causing respiratory problems, there was no stopping the onward rush into new and existing territory. BTOG went ahead as planned in January, bringing news of trials updates and networking for future collaborations.

However, by the beginning of February, dark clouds were gathering and whilst we did manage the trip to Manchester for the Ladies' Lunch, by the beginning of March, we knew we were saying a last 'hurrah', at least for the time being.

The news from northern Italy made for grim viewing and the race began to ensure that hospitals in the UK would not suffer the same fate. For several weeks from mid-March, the cry was all about 'upskilling' and 're-providing', along with ensuring adequate amounts of PPE and training on doffing and donning; words that were new to the vocabulary of the average specialist nurse, but we were keen to help where we could.

Mesothelioma UK very generously contacted our 'home' hospitals and advised that we could be freed up to help on the frontline. I personally had not worked on a ward since 1996 so had many sleepless nights over that period, wondering if I was up to the challenge and more pertinently, what that challenge would be. I worried, having seen the horror that befell Italy, that I would be somehow irrevocably changed by the experiences we were anxiously awaiting, not that I was concerned about having difficult conversations - that comes with the specialist nurse role - but perhaps the volume of those conversations and the fact that for the most part, I would be having them virtually made for a very tense and unsettling few weeks.

I vacillated between feeling I was on a beach waiting for a huge tsunami to wash over me or standing on the edge of a cliff looking down into the blackness, not knowing if it was safe to jump. On top of that, I worried for my team who also faced the prospect of re-deployment, but mostly, our patients who were incredibly scared and anxious about a virus that caused respiratory issues when they were already fighting a disease that had damaged their lungs.

It became clear within a few weeks, albeit it seemed like a lifetime, that Devon and Cornwall had not been as severely affected as other places and thanks to our incredibly amazing pleural fellows, we kept the National Optimal Lung Cancer Pathway operating. Our navigator did a great job, working from home whilst shielding her vulnerable husband, organising chest X-rays and CT scans in a timely manner.

The pleural fellows ran four out of our previous six clinics and kept the diagnostic service running so we continued to diagnose both lung cancer and mesothelioma. Having switched to a 'virtual' platform for the weekly MDT, we were able to discuss the cases and refer to oncology as needed.

Derriford made an early decision to move both the oncology ward and the chemotherapy day unit to the Nuffield Hospital, situated across the road from our main workplace, so it was relatively easy to work over the two sites and meant we could keep our most vulnerable patients safe. Home Park (home ground of the mighty Plymouth Argyle football club) offered their stand for out-patient phlebotomy, again negating the risk of attending Derriford.

And so life went on, with University Hospitals Plymouth's motto 'One big team' sounding more apt than ever. I had offered my services to the hospital palliative care team but luckily was never needed and our team managed to stay together throughout, which I credit 100 per cent with keeping me sane. We spent our days making COVID-19 welfare calls and checking up on our most vulnerable by whatever means we could. The Mesothelioma Support Group went from meeting twice monthly to zero in short order and both myself and the trustees scrambled for ways to support our members as they were dealing with shielding, their disease and treatment.

Finally, we settled on a weekly Zoom coffee meeting. The 'room' opens at 11am every Thursday and patients and carers can drop in for as long as they like. It has been an amazing success but has its limitations when trying to integrate new patients and I for one can't wait until I can actually have the group together under one roof (or outdoors, if it has to be). The trustees of SWASAG have been incredibly supportive of both me and the patients and I could never have managed without them.

So, we are now in August and March seems like a long time ago. We have all learnt new coping methods as we go forward into our new 'normal', and the lessons that I have learned are not really new but simple reinforcements of things that existed; namely, team work is the key to keeping sane and the support that it brings is immeasurable, both at local level and through Mesothelioma UK.

Our WhatsApp group has been a lifesaver at times as we have supported each other through the dark days with humour and pathos. I remain, as ever, in awe of my colleagues up and down the country, but resolutely glad that we did this together. Whilst we remain unsure regarding the future, I know we will cope together and that Team Meso will continue to be a force for good, supporting each other and those we have the privilege to call our patients.

Financial impact of COVID-19

COVID-19 has affected all charities and Mesothelioma UK is no exception. Our nurses and our operational staff have gone above and beyond to keep our free information line open and to support patients whenever and however they need it. However, as some normality returns across the UK, charities are still struggling with the financial impact of COVID-19. This year will see a significant drop in our income, and we know that there are many supporters who have followed our journey and watched us grow over the past ten plus years who will be as saddened as we are that we cannot realise some of our ambitions in the coming year.

However, with the dedicated and generous support of our mesothelioma community, we will continue to provide much-needed support to mesothelioma patients and carers across the UK. Thank you from the bottom of our heart to everyone who has supported us so far and please continue to give when you can.

To get involved with Mesothelioma UK and donate, please visit www.mesothelioma.uk.com/donate

New Clinical Nurse Specialist appointed for East Kent

Toni Fleming has been appointed as a new Mesothelioma UK Clinical Nurse Specialist for East Kent Hospitals University NHS Foundation Trust. Toni Fleming will be based at Kent and Canterbury Hospital and will be supporting mesothelioma patients across the East Kent region with their treatment and care.

Toni will be working alongside Mesothelioma UK Clinical Nurse Specialist, Louise Gilham in Kent. The new role will be fully-funded by the Mavis Nye Foundation for the first two years. The Mavis Nye Foundation was set up three years ago by Mavis Nye, the longest-living mesothelioma immunotherapy patient in the UK and a patient advocate for Mesothelioma UK.

Toni Fleming has been a Lung Cancer Nurse Specialist since 2004 and a General Nurse since 1995. She has worked in lung cancer and palliative care throughout her career.

Commenting on her new role, Toni said: "East Kent has a particularly high proportion of mesothelioma patients so I'm delighted to be working with Louise and the wider Mesothelioma UK team to support our patient community. I've been working with Mavis since her initial diagnosis and the support of her Foundation and donors has been critical in establishing this new role."

Mavis Nye said: "The Foundation came about because I was surviving longer than my diagnosis and I wanted some way to pay back for the wonderful care that I was getting from the NHS. I had run the groups on Facebook as I wanted to share all of the information that I was researching. Eleven years ago, there wasn't so much available and Googling only brought up horror stories. I wanted to spread hope.

"The Foundation was born and money was, and still is being donated so I was able to establish my legacy. I'm really thrilled to have a Mesothelioma UK nurse in East Kent and even more thrilled that Toni accepted the post. She will take my legacy forward.

"The Foundation is still having successes so we have plans for this year to follow the research grant that we awarded and we will be offering more grants in 2021. I'm alive today because of research so it really is important in the story of mesothelioma that we are all playing our part."

Mary Mulhall, solicitor at Hugh James and Chair of the Mavis Nye Foundation said: "It is thanks to the generosity of so many people who have supported the Mavis Nye Foundation with their donations that we are able to fund this post. It is essential to have specialist nurses supporting mesothelioma patients and we are delighted to be able to contribute in this way and support a second dedicated Mesothelioma UK nurse in Kent."

Lorraine Creech, Head of Nursing for Mesothelioma UK, added: "We are delighted to welcome Toni to the Mesothelioma UK Clinical Nurse Specialist Team. Toni has a wealth of experience in lung cancer, mesothelioma and palliative care, and she has already become integral to our nursing team.

"We know that there is a high incidence of mesothelioma within the Kent and Medway Cancer Alliance according to the National Mesothelioma Audit Report (2020) and we are pleased that Toni will be able to work alongside Louise Gilham with the aim of improving the support, care and treatment for people with mesothelioma. We are extremely grateful to the Mavis Nye Foundation for providing funding for this new role."

Our nursing team

Currently, we have 22 fully supported Clinical Nurse Specialists in 20 NHS Trusts throughout the UK. We have five adopted Clinical Nurse Specialists in three NHS Trusts and three Clinical Nurse Specialists who are affiliated to Mesothelioma UK in three NHS Trusts.

They are all available to offer support and expertise to mesothelioma patients, their families and the wider mesothelioma community. We have a further three posts in the recruitment phase in Essex, Sunderland and Huddersfield.

Since the start of the COVID-19 pandemic, we have been running the regular Tuesday morning live Facebook Q&A chat at 11am and the live Facebook quiz at 8pm on the first and third Tuesday of the month. These have been well received and we have been grateful for your interaction.

We will continue with these events for now and any changes to schedules will be circulated via social media. We have also conducted a number of interviews that we hope you have found informative and enjoyable. Thank you to all who have participated.

It is with deep sadness that we report that Susan Jackson, Pleural Nurse at Wythenshawe Hospital, part of the Manchester University NHS Foundation Trust, died in a tragic incident on 23 August. Susan will be known to many people who were diagnosed and cared for at Wythenshawe Hospital. She was very well respected and an extremely professional nurse. She was kind, caring and supportive. She will be greatly missed by patients and her colleagues. Sue was a lovely person inside and out, and our thoughts are with her family and friends at this very sad time.

Lorraine Creech, Head of Nursing at Mesothelioma UK

100 schools and workplaces sign up to UKNAR's Asbestos SMART trials

Following the announcement of UK National Asbestos Register (UKNAR) CIC's partnership with Mesothelioma UK in the last edition of Mesothelioma Matters, over 50 schools are now going to be trialling UKNAR's Asbestos SMART system from September. In addition, Knight Frank, the UK's leading independent real estate agency has adopted Asbestos SMART technology across its prestigious London commercial property portfolio.

The newly formed CIC (Community Interest Company) has been working hard over lockdown to hit the safeguarding message home to schools and local authorities with the aim of protecting onsite maintenance teams, contractors, pupils and staff, to improve the management of asbestos in the 80 per cent of UK schools where it remains a persistent and potentially deadly issue.

Over the last few months, UKNAR's school campaign has been encouraging UK schools to sign up to the national database. In turn, this currently provides free early adopter trial access to Asbestos SMART; a very simple, contactless, paperless QR code system to help schools and dutyholders manage their asbestos registers and asbestos risks more effectively to prevent unnecessary asbestos exposures.

As well as saving lives, it saves administration time and money and potentially expensive disruption caused by accidental asbestos disturbances or delays to works. In the commercial property sector, UKNAR's Asbestos SMART system will help Knight Frank to create a safer environment for contractors, landlords and building occupiers.

By simply scanning a unique site-specific QR code, Knight Frank's estates management and building maintenance teams will have instant access to all known asbestos across the property portfolio, via mobile phone or tablet.

Jason Taylor, Head of Facilities Management, Knight Frank, London, comments: "Asbestos SMART proactively promotes good public health and safety practice and helps us to look after everyone who uses our buildings. Today everyone has access to a mobile phone, so by using the latest simple smart technology, we can protect contractors, visitors and occupiers alike."

Andrew Paten, Co-Founder, UKNAR, says: "Our first official signing for Asbestos SMART in the commercial property sector is with Knight Frank and we are truly delighted that Mesothelioma UK directly benefits from this partnership as well as building occupiers across Knight Frank's London property portfolio.

"We hope it will be the start of many others in this space following Knight Frank's example. We are very encouraged by the in-roads we have been able to make in education and commercial property over the last few months – albeit this is just the tip of the iceberg, but we are heading in a very positive trajectory."

The new partnership with Knight Frank represents a significant milestone for UKNAR as a newly formed CIC and its commitment to pursuing a social purpose over making profits for shareholders. As a direct beneficiary, Mesothelioma UK will receive five per cent of all Asbestos SMART license fees.

UKNAR is now proactively looking to expand its reach in education, public sector, social housing and commercial property – if you know a workplace that could benefit from adopting Asbestos SMART, please get in touch with Stuart Tower at stuart.towers@uknar.org

EVENTS

Action Mesothelioma Day 2020

This year's Action Mesothelioma Day was inevitably very different to previous years. Mesothelioma UK collaborated with the UK Mesothelioma Alliance (UKMA) and produced a 'virtual' event.

We hosted two Facebook Live sessions before and after the main UKMA event and had around 2,000 views. We also produced AMD packs that included a paper dove, on which a personal message to loved ones could be written, and a packet of Forget-me-Not flower seeds. We also ran a name roll on the website homepage for the whole day that showed personal messages from the friends and families of those affected by mesothelioma.

We'd like to thank everyone who watched online, bought a pack, ordered a name roll or made a donation on the day. It was good to work with the UKMA to be part of a national, online event. We hope that you managed to watch some of the speakers (healthcare experts, patients, and carers) and look forward to Action Mesothelioma Day 2021.

Bristol and Beyond Asbestos Family Support Group's AMD

Bristol and Beyond Asbestos Family Support Group took things online this year and held a virtual Action Mesothelioma Day get together on 3 July 2020. Things were rather different than usual but members enjoyed chatting about their lockdown gardening, and also heard tips on resilience and keeping positive in these unprecedented times. It was great to see new and old faces, to raise awareness, remember loved ones and to catch up with friends.

Bristol and Beyond Asbestos Family Support Group is a really special group and new members are always welcome. Further information can be found on the website at www.bristolasbestossupport.co.uk or by calling Sarah Smith on 0117 414 1900.

Patient and Carer Day 2020 is going digital

Join us this year as we host our annual Patient & Carer day 'virtually' on Friday 2 October 2020. It will be a day of learning, sharing and also meeting others with similar experiences via our virtual lunch breakout rooms.

You can learn the latest on mesothelioma clinical trials, treatments and research from clinical experts, and hear personal stories from patients. The event is free for all to attend although a donation to support Mesothelioma UK would be gratefully accepted.

Please visit www.mesothelioma.uk.com/pcday to find out more information and to book your place. Our annual awards evening that usually takes place the night before the Patient & Carer Day is unfortunately postponed until 2021, date to be confirmed.

STUDIES AND REPORTS

Update on studies funded by Mesothelioma UK

By Dr Lynn Furber, Research Manager at Mesothelioma UK

Project title	Lead researcher	Completion due date	Progress
Exploring clinical decision-making in mesothelioma treatment pathways across three NHS trusts: a mixed methods study	Cathy Henshall	October 2020	Project placed on hold due to COVID-19. The hospital trusts suspended all research non COVID-19 related.
Healthcare workers and mesothelioma: experiences of presentation, diagnosis, treatment and care: Healthcare Worker Mesothelioma Asbestos Guidance Study (MAGS)	Peter Allmark		This study is now complete and an end of study report is due to be published shortly.
Understanding the role of the CNS in meeting the palliative care needs of patients and families: a mixed methods study	Clare Gardiner	January 2021	In progress.
MEDUSA: MESOUK 17-8. Mesothelioma Evolution: Deciphering drUgable Somatic Alterations	Edward Hollox		This study has been extended to 2021 to allow more patients to be recruited into the study.
Gendered Experience of Mesothelioma Study (GEMS)	Angela Tod	June 2020	This study is drawing to a close and an end of study report is due in the near future.

Project title	Lead researcher	Completion due date	Progress
Genomics of Peritoneal Malignancy including rare forms of mesothelioma	Sarah Ennis	Sept 2020	This study has been placed on hold and delayed due to COVID-19.
Living well with cancer	Karen Lord	April 2021	This study is ongoing as planned and data analysis is currently being reported.
The experience of long-term survival in people affected by pleural mesothelioma and their carers	Matthew Johnson		This study has been granted this year through LCNUK but the start date has been delayed until January 2021 due to COVID-19.
Immunotherapy for malignant mesothelioma using IL-6-neutralising CAR T-cells	John Maher		This study is due to complete in February 2021.
HypoxamiRd as a new target for treatment of asbestos induced cancer.	Marija Krstic-Demonacos		This study is ongoing.

Study into the psychological effects of mesothelioma

Mesothelioma UK has funded a research team at the University of Sheffield to carry out a review of the psychological effects of mesothelioma on patients and carers. The review is now complete and published in the journal, Psycho-Oncology.

The study concluded that the evidence indicates that mesothelioma, with its high symptom-burden, incurability, rarity and asbestos-related causation, leads to complex and inter-relating psychological effects on patients and carers - both negative and positive.

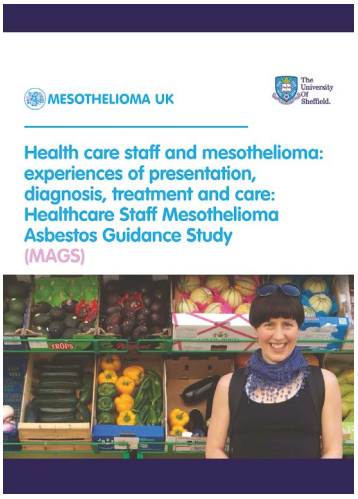
The study recommends more research into this area with a particular focus on carers. The report is available to read online at https://onlinelibrary.wiley.com/doi/full/10.1002/pon.5454

MAGs study explores mesothelioma and healthcare workers

Mesothelioma UK, alongside donations from the family and friends of the late Dr Mags Portman, has funded a study looking at healthcare workers and mesothelioma. The Healthcare Worker Mesothelioma Asbestos Guidance (MAGs) study interviewed patients who are, or were healthcare workers. It was conducted by the Mesothelioma Patient Experience Research Group at the University of Sheffield.

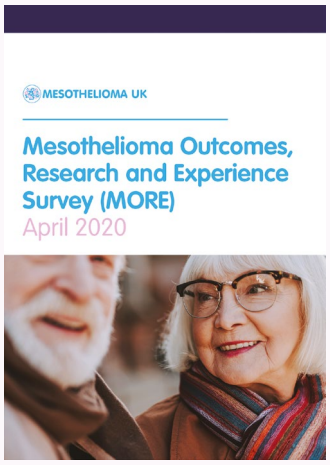
Participants included both clinical staff, such as doctors and nurses, and non-clinical staff, such as medical secretaries, cleaners, porters and maintenance staff.

The study aimed to explore the experiences of healthcare workers with mesothelioma and develop recommendations for increasing awareness of the risk to healthcare workers. The study is now complete and a report detailing the findings and recommendations will be available on our website soon.



Patients have their say in MORE survey

In 2019, Mesothelioma UK offered mesothelioma patients the opportunity to describe their experience of investigations, treatment and care as part of an investigation into their experiences.



The MORE survey (Mesothelioma Outcomes, Research and Experience) was designed to enable Mesothelioma UK to inform healthcare providers about what is being done well, what could be improved and hopefully where there are variations in treatment and care. It will also help us to develop our services to complement those of the NHS and prioritise what kind of support services we should be offering.

The survey consisted of three sections – patient experience of care, quality of life and clinical information. Based on the feedback that we received from 503 responders, we have produced a report containing the results and recommendations based on the findings.

The survey highlights confidence and satisfaction across many areas but it has also revealed a number of interesting findings that Mesothelioma UK hopes to address over the coming months and years. We will circulate the report to the wider mesothelioma community and healthcare providers, and will make it available to view on our website shortly.

New publications

By Pip Divall, Clinical Librarian Service Manager at University Hospitals Leicester NHS Trust

This section details new publications from the last three months.

New scientific research
Clinical Outcomes With Recurrence After Pleurectomy/Decortication for Malignant Pleural Mesothelioma.
Author(s): Nakamura, Akifumi; Takuwa, Teruhisa; Hashimoto, Masaki; Kuroda, Ayumi; Nakamichi, Toru; Matsumoto, Seiji; Kondo, Nobuyuki; Kijima, Takashi; Yamakado, Koichiro; Hasegawa, Seiki
Source: The Annals of thoracic surgery; May 2020; vol. 109 (no. 5); p. 1537-1543

Elevated Circulating Activin A Levels in Patients With Malignant Pleural Mesothelioma Are Related to Cancer Cachexia and Reduced Response to Platinum-based Chemotherapy.
Author(s): Paajanen, Juuso; Ilonen, Ilkka; Lauri, Helena; Järvinen, Tommi; Sutinen, Eva; Ollila, Hely; Rouvinen, Eeva; Lemström, Karl; Räsänen, Jari; Ritvos, Olli; Koli, Katri; Myllärniemi, Marjukka
Source: Clinical lung cancer; May 2020; vol. 21 (no. 3); p. e142

Confidence interval function analysis to evaluate the risk of mesothelioma among an expanded international cohort of cosmetic talc miners and millers.
Author(s): Marsh, Gary M; Ierardi, A Michael
Source: Regulatory toxicology and pharmacology : RTP; Aug 2020; vol. 115 ; p. 104696

Laser ablation inductively coupled plasma mass spectrometry as a Novel Clinical Imaging Tool to Detect Asbestos Fibres in Malignant Mesothelioma.
Author(s): Voloaca, Oana M; Greenhalgh, Calum J; Cole, Laura M; Clench, Malcolm R; Managh, Amy J; Haywood-Small, Sarah L
Source: Rapid communications in mass spectrometry : RCM; Jul 2020 ; p. e8906

Predictors and Outcomes of Surgery in Peritoneal Mesothelioma: an Analysis of 2000 Patients from the National Cancer Database.
Author(s): Bijelic, Lana; Darcy, Kathleen; Stodghill, Joshua; Tian, Chunqiao; Cannon, Timothy
Source: Annals of surgical oncology; Aug 2020; vol. 27 (no. 8); p. 2974-2982

Mesothelioma Biomarkers: A Review Highlighting Contributions from the Early Detection Research Network.
Author(s): Pass, Harvey I; Alimi, Marjan; Carbone, Michele; Yang, Haining; Goparaju, Chandra M
Source: Cancer epidemiology, biomarkers & prevention: a publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology; Jul 2020

Questioning the prognostic role of BAP-1 immuno-histochemistry in malignant pleural mesothelioma: A single centre experience with systematic review and meta-analysis.
Author(s): Cantini, Luca; Pecci, Federica; Murrone, Alberto; Tomasetti, Marco; Copparoni, Cecilia; Fiordoliva, Ilaria; Morgese, Francesca; Rinaldi, Silvia; Mazzanti, Paola; Rubini, Corrado; Cimadamore, Alessia; Barbisan, Francesca; Giampieri, Riccardo; Scarpelli, Marina; Santarelli, Lory; Berardi, Rossana
Source: Lung cancer (Amsterdam, Netherlands); Aug 2020; vol. 146 ; p. 318-326

Clinical Trials Eligibility of Patients With Malignant Pleural Mesothelioma: Use of Novel Therapies and Outcomes.
Author(s) Lau ; Boyer, Michael; Lee, Jenny H.; Kao, Steven
Source Clinical Lung Cancer; Jul 2020; vol. 21 (no. 4); p. 378-378

Gender differences in molecular-guided therapy recommendations for metastatic malignant mesothelioma.
Author(s) Taghizadeh ; Zöchbauer-Müller, Sabine; Mader, Robert M.; Müllauer, Leonhard; Klikovits, Thomas et al.
Source Thoracic Cancer; Jul 2020; vol. 11 (no. 7); p. 1979-1988

Genomic analysis in short- and long-term patients with malignant pleura mesothelioma treated with palliative chemotherapy.
Author(s) Torricelli ; Saxena, Alka; Nuamah, Rosamond; Neat, Michael; Harling, Leanne et al.
Source European Journal of Cancer; Jun 2020; vol. 132 ; p. 104-111

Breath Analysis for Early Detection of Malignant Pleural Mesothelioma: Volatile Organic Compounds (VOCs) Determination and Possible Biochemical Pathways.
Author(s) Di Gilio ; Catino, Annamaria; Lombardi, Angela; Palmisani, Jolanda; Facchini, Laura et al.
Source Cancers; May 2020; vol. 12 (no. 5); p. 1262-1262

Lung Asbestos Fibre Burden and Pleural Mesothelioma in Women with Non-occupational Exposure.
Author(s) Barbieri ; Somigliana, Anna; Chen, Yao; Consonni, Dario; Vignola, Roberto et al.
Source Annals of Work Exposures & Health; Apr 2020; vol. 64 (no. 3); p. 297-310

Qualitative studies and patient experience
What are the psychological effects of mesothelioma on patients and their carers? A scoping review
Author(s) Sherborne, Virginia; Seymour, Jane; Taylor, Bethany; Tod, Angela
Source Psycho-Oncology; Jul 2020

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

UHL Clinical Librarian Service
"bringing you the evidence"

PATIENT STORIES

My Mesothelioma Story

By Dr Maija Maskuniitty (Centre Manager, NCMR)

Last year, the National Centre for Mesothelioma Research (NCMR) at Imperial College London was honoured to talk to some amazing mesothelioma patients and carers for the NCMR 'My Mesothelioma Story' audio interview series. The informative and touching interviews are an opportunity to hear the stories of people whose lives have been affected by this devastating disease.

It was a real privilege for the NCMR's early career researchers who assisted with the interviews to have the opportunity to meet and talk to mesothelioma patients and patient carers. It allowed these aspiring scientists to see the human perspective of the disease and to understand even more how important their research is to try and improve the lives of patients and their families.

The interviews were made in collaboration with Mesothelioma UK as part of the NCMR's contribution to the Great Exhibition Road Festival, of which Imperial College was part.

Huge thanks to all the interviewees and best wishes from the NCMR to the whole mesothelioma community.

You can listen to the interviews at: www.imperial.ac.uk/national-centre-mesothelioma-research/public-engagement/my-meso-story/

For more about the NCMR's participation in the Festival, visit: www.imperial.ac.uk/national-centre-mesothelioma-research/public-engagement/imperial-festival/

Poet writes about her mother's mesothelioma experience

By Victoria Bennett

At 82, my mother thought she had outwitted mesothelioma. She had watched her younger sister and brother die from it but she thought she had been lucky enough to be spared the same fate.

After all, when she'd been worried about a persistent cough back in 2011, the doctor had told her mesothelioma was a rare disease and that it was 'almost impossible for all the children in one family to die from it'. When she was still coughing three years later, she told herself it was just a stubborn chest infection. When she found she was struggling to find the energy to do basic tasks, she blamed it on her age. It was nothing, she told herself, but I was worried it was more and eventually, she agreed to go and see a different GP.

After listening to her chest, she was sent for an X-ray which was quickly followed by a CT scan and then a PET scan. My mother still insisted it was a rare disease and she would be okay. Sadly, this was not the case.

What followed was nine months of tests, procedures and confusion, as consultants and doctors first diagnosed then re-diagnosed my mother, telling her it was malignant mesothelioma, then benign mesothelioma, then pleurisy, then 'nothing to worry about', then oesophageal cancer, then lymphoma and finally, back to mesothelioma.

There were times that I wished I had never told her to go to the doctors in the first place. No-one seemed to know what was happening and no-one could help her. On 24 December 2014, after nine months of investigations and increasing illness, she was finally diagnosed with advanced mesothelioma. She was offered a small amount of palliative chemotherapy and an increasing amount of drugs.

Over the next eleven months, I cared for her and continued to be her advocate in the strange world of terminal caregiving. It was a difficult time, demanding more of me than I thought I could give at times, especially as I was also the primary carer for my young, disabled son, but it was also a precious and gifted time. As her world grew smaller and mine with it, we found joy in what was close to us: spending time together, sitting in the garden, watching the days unfold. I was so grateful for the support of Mesothelioma UK during this time, especially during the difficult months leading up to final diagnosis, as well as the support of our local Macmillan Nurse and Hospice At Home service. These charities made it possible for me to advocate for my mother, get the best care I could for her and also supported me so that I could continue to care for her right to the end.

My mother was called Maureen. She was an artist and a mother and a wonderful friend. She didn't like to be called brave because, as she said, she didn't have much choice about it, but she was resilient and generous and strong. She died at home on 1 December 2015, age 83, with her husband of 63 years, her children and grandchildren by her side. On her gravestone, it says that she made the world a more beautiful place to live in, and she did.

It was a terrible ending for a wonderful woman. She, like her brother and sister, were exposed to asbestos fibres during childhood. Their lives were ended before their time, simply because their father was a joiner who had worked during the war cutting asbestos boards. There would be no culpability, no acknowledgement of the human cost of that work. After all, it was long ago. It made me so angry at times that their deaths were so invisible, that somehow their suffering and courage was to go so unnoticed.

I knew after my mother died that I wanted to write something about her death, not only for myself to help me come to terms with the loss, but also to raise awareness of the day-to-day experience of caregiving through terminal mesothelioma. My mother was afraid of dying, not so much the spiritual side of it, but the reality of the sickness. She had nursed her sister through mesothelioma and knew what it could be like. She often asked nurses to tell her what was likely to happen next for her physically, but found that few people were willing to talk about the intimate details of these things.

When it came to writing the poems that make up *To Start The Year From Its Quiet Centre*, I wanted to try and write about what this year of caregiving had been like — the quiet hours of waiting, the restructuring of life around the inevitable, the physical demands of cancer on the patient and carer, and finally, about the letting go, not just of a loved one but also of the role of caregiver. The collection begins with the diagnosis and our movement into the medical world of cancer-care and ends in the 'quiet centre' of the year after loss.

In between, we share the private and intimate moments of dying and offer a personal meditation on loss and love that tell the story of a relationship between daughter and much-loved mother, a relationship that is transformed through grief. The collection is written in memory of my mother, Maureen Marie Bennett. It is my hope that, through sharing these poems, I can offer a quiet moment to those who share this journey and raise awareness of mesothelioma, the devastating impact it has on those diagnosed and those who care for them, and honour the strength and beauty of those who walk this path.

Victoria's latest poetry pamphlet, *To Start The Year From Its Quiet Centre*, is available to order from www.indigodreams.co.uk/victoria-bennett/4594998880

Mesothelioma patient speaks out

Errol Lee, a man in his 70s who worked for many years near Melton Mowbray, has decided that it is time to speak out about how he contracted the disease, having just succeeded in obtaining a six-figure compensation settlement from his former employers' insurers.

His hope is that if there are any former work colleagues who might also be showing symptoms of mesothelioma, they too may get a speedy diagnosis and benefit from some financial compensation to give them access to the best possible medical treatment.

Mr Lee spent over 25 years working for the construction company A J Stimson & Son and latterly A J Stimson & Son (Somerby) Ltd as a joiner and a carpenter. The firm's projects included new builds and renovations in both the residential and commercial sectors. Among the tasks Mr Lee carried out were removing and replacing asbestolux soffits, installing asbestolux ceilings in garages, fitting asbestos bath panels and replacing corrugated asbestos cement sheets in farm buildings. He also spent time working in the firm's joinery shop where he cut asbestolux sheets to size and swept up the dust created by the fibres.

Throughout the entire period of Mr Lee's employment by the construction company, his employer's failed to take adequate measures to avoid or minimise the release of asbestos fibres into the atmosphere. They gave no warnings about the dangers of working with asbestos and didn't provide any suitable protective equipment. Mr Lee's case was supported by Ashtons Legal.

Mr Lee, who now lives in Cambridgeshire having relocated to be closer to his daughter and her family while battling his illness, is being treated at Addenbrooke's Hospital and is supported by Mesothelioma UK nurse, Kate Slaven who is based at the Royal Papworth Hospital.

He has been helped by, and become a supporter of, Mesothelioma UK and following settlement, he has donated valuable funds to the charity.

Lorraine Creech, Mesothelioma UK Head of Nursing, commented: "I would like to thank Mr Lee for raising awareness about his diagnosis of mesothelioma after being exposed to asbestos during his career as a joiner.

"The UK has the highest incidence of mesothelioma in the world with approximately 2,700 people being diagnosed each year. The awareness that he is providing will hopefully assist with earlier diagnosis and treatment for others like himself, who find themselves in such a difficult situation through no fault of their own.

"Mesothelioma UK works tirelessly and passionately to improve the treatment, care and support for all people in the UK with mesothelioma and their carers. We are dedicated to raising the profile of mesothelioma to help prevent future cases and make mesothelioma matter."

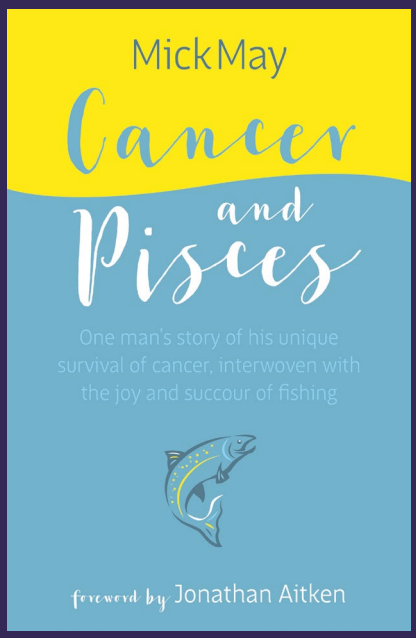
Kate Slaven, Mesothelioma UK and Lung Cancer Clinical Nurse Specialist at Royal Papworth Hospital NHS Foundation Trust added: "I want to pass on a massive thank you to Errol and his family for his very generous donation to Mesothelioma UK. I am lucky enough to be one of the nurses caring for Errol and as a Mesothelioma UK Specialist Nurse, I am aware of what a difference this will make in caring for all of our patients."

Cancer and Pisces

In 2013, Mick May was diagnosed with the fatal asbestos-linked cancer, mesothelioma, whose average medical life expectancy is ten months.

Seven years later he is flourishing, full of joie de vivre, with a long-life expectancy ahead of him. His case has made medical history and is giving new hope to a multitude of terminally ill cancer sufferers around the world.

Mick's new uplifting autobiography, 'Cancer and Pisces' tells of his tales of fishing with cancer, and is suffused with humour and elation. Mick's medical journey makes for a fascinating and yet humorous read as it weaves from the pain of his many treatments to the pleasures of his frequent fishing trips to exotic British and international rivers.



Threaded into this are snapshots of Mick's creation and leadership of a leading offender rehabilitation charity; his deepening religious faith; his successful legal action against the merchant bank whose offices exposed him to asbestos in the 1980s; his chairmanship of a school ravaged by the 2017 Grenfell Tower fire tragedy, and the happiness of his family life with his remarkable wife and children.

Mick May spent 20 years in finance where increasingly he saw himself as the worst banker in the City of London. His second career saw him set up and grow the social enterprise Blue Sky, once described by David Cameron as 'the only company in the country where you need a criminal record to work there'.

Over the past decade and a half it has succeeded in employing almost 2,000 released prisoners. In 2016 his work with ex-offenders was recognised by the award of an OBE. Since retirement on medical grounds in 2015 he has chaired the boards of a couple of charities and an academy. Mick is an avid reader of history books and an extraordinarily keen angler. He continues to fish to this day.

Cancer and Pisces is published by Quiller Publishing and is available now for £14.99.

CLINICAL TRIALS

New immunotherapy drug on NHS

NHS England and NICE have approved the use of immunotherapy drug, nivolumab, as a second line treatment.

On Monday 3 August 2020, NHS England updated its medicines list in line with COVID-19 risk factor analysis. As part of this review, NHS England, alongside the Chemotherapy Reference Group have looked at a number of drugs for different cancers which are felt to have a low risk of suppressing the immune system. This is important in light of the COVID-19 pandemic as it helps the NHS treat cancer patients whilst minimising the risk of contracting COVID-19 due to a compromised immune system.

One of the drugs added to the interim register was nivolumab which is an immunotherapy drug that has shown benefit in a number of cancers including mesothelioma. The MARS2 and Checkmate 743 trials showed clinical benefits for mesothelioma patients who were treated with nivolumab alone or nivolumab and Ipilimumab.

Nivolumab will now be available on the NHS as a second line treatment for patients who have already had chemotherapy as their first line treatment and who have progression of their mesothelioma. Until now, mesothelioma patients could only access this drug as a private patient, meaning many patients missed out on this potentially beneficial treatment. The NHS interim guidance lasts until April 2021 which means that a greater number of patients will have access to this drug. Patients should talk to their healthcare team about the availability of the drug or call our information line on 0800 169 2409.

Mesothelioma UK is delighted with this announcement from NHS England in light of the very limited second line treatment options that are available for mesothelioma patients. Unfortunately, patients in Scotland and Wales will not have access to nivolumab yet and we will wait to see if NHS Scotland and NHS Wales follow NHS England.

ATOMIC-Meso

This trial studies (ADI-PEG 20) plus pemetrexed and cisplatin (or carboplatin) (ADIPemCis) (ATOMIC-Meso Phase 2/3 Study) (ClinicalTrials.gov Identifier: NCT02709512) as first-line chemotherapy in the sarcomatoid and biphasic subtypes of MPM. These histologies are known to be very aggressive, and have a worse prognosis than epithelioid MPM. In a prior phase 1 study (NCT02029690), the ADIPemCis combination was found to result in an encouraging overall response rate with prolonged overall survival in some patients, with non-epithelioid MPM and nonsquamous non-small cell lung cancer. As such, the ADIPemCis combination has been moved forward into the next stage of clinical investigation.

ADI-PEG 20 depletes arginine, and is expected to enhance the effects of the standard-of-care chemotherapy (pemetrexed and cisplatin). Thus, this metabolic therapy is another mode of attack on the cancer cell. ADI-PEG 20 alone, and in combination therapy, has been well tolerated, with adverse effects consistent with what would be seen with chemotherapy alone.

This trial is now in the phase 3 portion with more than 200 of the required 386 patients enrolled.

If would like to discuss the trial in any more detail or explore whether it is appropriate for you as a patient, please discuss with your clinical team or contact Mesothelioma UK and one of our nurses will be glad to talk with you.

MARS 2

MARS 2 is a randomised clinical trial comparing surgery (extended pleurectomy decortication) versus no surgery in patients diagnosed with pleural mesothelioma, with respect to overall survival and aims to recruit 328 participants.

As of March 2020, MARS 2 was recruiting to time and target, with recruitment set to be completed by the end of July 2020. However, the study was paused in March 2020 due to the COVID-19 pandemic. Sites were instructed to halt all recruitment and screening study activities but to continue with follow ups and data collection. At the time of the pause, 303/328 (92 per cent) participants had been randomised to the study.

In May 2020, the recruitment pause was lifted for all sites who confirmed that they had capacity to restart. In light of the COVID-19 situation, the recruitment end date has been extended and the study has now recruited 319 patients (at the time of this article).

Once the trial has completed accrual, the decision on the conduct of (extended) pleurectomy / decortication surgery for the radical treatment of mesothelioma would fall back to local protocols and policies until the results of MARS 2 are available at the end of 2022.

The protocol paper for MARS 2 was accepted by BMJ Open (publication date TBC).

MiST

The MiST 3 arm pembrolizumab and bemcentinib in relapsed mesothelioma is now open at University Hospitals of Leicester: PI Professor Dean Fennell.

This arm is due to be opening up in The Christie, Manchester: PI Dr Matthew Krebs and Newcastle (Bobby Robson Unit) PI: Dr Alastair Greystoke shortly. MiST 1 & 2 are now closed, as recruitment is complete and MiST 4: (atezolizumab and bevacizumab) will be due to re-open in October 2020 at Leicester, Southampton and Newcastle.

INFINITE

The second/third line phase III trial, INFINITE, had to close to recruitment at several sites but has reopened at Wythenshawe Hospital, Manchester with Dr Taylor, the Beatson West of Scotland Cancer Centre with Dr Steele and Royal Marsden, London with Professor Popat.

BEAT-meso

Previous trials of chemotherapy and immunotherapy have shown activity in patients with mesothelioma. Therefore, the BEAT-meso phase 3 open-label randomised control trial aims to determine if the addition of immunotherapy (Atezolizumab) to chemotherapy (Carboplatin /Pemetrexed) and Bevacizumab is superior to no immunotherapy, in treatment-naïve patients with malignant pleural mesothelioma.

Patients receive four to six cycles of Carboplatin/ Pemetrexed/Bevacizumab +/- Atezolizumab every three weeks, followed up maintenance Bevacizumab +/ - Atezolizumab until progression, death or up to two years of treatment.

Professor Popat is the global lead investigator for this exciting trial which could significantly improve the survival of patients with this poor prognostic cancer and change practice in the future.

NEMO

Previous studies have shown the addition of anti-angiogenic agents to chemotherapy improved overall survival for patients with malignant pleural mesothelioma (MPM) compared to chemotherapy alone. Therefore, the double-blind randomised phase 2 NEMO study compares maintenance oral Nintedanib 200mg twice-per-day versus placebo in patients with MPM who have modified-RECIST-defined stable disease or response after first line platinum-pemetrexed chemotherapy.

An important inclusion criterion is that randomisation must occur within 60 days from the last dose of platinum chemotherapy; thus timely referral is crucial. Both trials are open and actively recruiting at the Royal Marsden Hospital.

SYSTEMS-2

Pain is a common symptom in malignant pleural mesothelioma and can be difficult to control with standard painkillers. The SYSTEMS study, published in 2015, showed that a radiotherapy dose of 20Gy over five days can be helpful for pain in about one third of patients, with minimal side effects. The SYSTEMS-2 study is testing whether a higher dose of radiotherapy, 36Gy delivered over two weeks, is more effective for pain control than the standard dose used in SYSTEMS. Whilst recent advances in radiotherapy technology have made it possible to safely give higher doses, we need to perform a clinical trial to make sure there is no increase in side effects.

We aim to treat 112 patients who have pain scores of ≥4/10, with either standard or dose-escalated radiotherapy. Pain scores will be measured before the treatment and afterwards, at weeks five and nine. To date, 89 patients have been registered for the study in 19 sites across the UK. Patients who would like to be considered for SYSTEMS-2 should contact their local clinical oncologist.

www.systems-2.co.uk

LEGAL PANEL

Geoff's story

When Deborah's dad Geoff was diagnosed with mesothelioma, despair set in until the family found Mesothelioma UK. Read Geoffrey's story here...

Geoffrey (Geoff) Horner was exposed to asbestos for 39 years, from the day he left school at 15 and started an apprenticeship as a joiner.

The Bradford man often disturbed asbestos while he refurbished council houses, worked on railway stations, shop refits and school repairs. Yet he knew nothing about its dangers until 2001 when he underwent training as part of a managerial promotion.

"As soon as he was aware of the dangers of asbestos he made sure his workers were protected, something no one ever did for him," said his daughter, Deborah Wilson. "I remember he even used to tell me and my husband to be careful when we were carrying out work on our own home. He worked hard all his life, but his job had given him a ticking time bomb in his lungs."

Geoff first noticed breathlessness doing things he would usually do with no problem, such as cutting the grass and swimming. Multiple scans and tests followed a visit to his GP and 14 months after a diagnosis of mesothelioma, he died aged 72.

Before he died, the grandfather of two was signposted by his clinical nurse specialists at Bradford Royal Infirmary to Mesothelioma UK and a local asbestos support group, Mesothelioma Support Yorkshire (MESSY).

"Simon, the nurse we met from the charity, helped us access clinical trials, which gave us a sense of hope and optimism we didn't have before," said Deborah. "Simon had endless amounts of time to talk to Dad about his options and to explain the advice he was getting from his consultants. Dad wanted to protect us from the realities of his disease so he didn't talk about his illness much to us but MESSY gave him the chance to speak to people going through the same thing. I don't know what we would have done without them."

Backed by his union and with help from Thompsons Solicitors, Geoff brought a claim against his employers for civil compensation. As part of the settlement, £2,500 was claimed back from the defendants in Geoff's legal case, to reimburse the charity for the costs of their specialist nurse who supported Geoffrey in accessing clinical trials, in addition to a settlement for Geoff's family.

Deborah added: "It means the world that we are able to give something back to the charity that helped my dad so much. This money will go towards giving someone else that vital support."

Helen Tomlin of Thompsons Solicitors, who represented the family, said: "Mesothelioma UK and our local support group, MESSY do incredible work for people and their families who have been affected by this devastating form of cancer. We were proud to obtain a sum for Mesothelioma UK and help Geoff hold his employers to account."

Helen Tomlin

The impact of COVID-19 on cancer services and mesothelioma

By Graeme Chisholm, Director at Novum Law

Graeme has extensive knowledge of personal injury law and he devotes his time to helping people to claim compensation in respect of asbestos-related illnesses.

Coronavirus has placed the NHS under intense pressure, forcing many hospitals and GP surgeries to change their working practices to focus on COVID-19 patients.

Patient safety campaigners and charities have been voicing their concerns about the impact the pandemic is having on cancer diagnosis, treatment, support and other services.

According to Cancer Research UK, one in three cancer patients say their treatment has been impacted by COVID-19, and around four in 10 people (42 per cent) also said their tests – including those to find out whether their cancer had spread or returned – have been affected.

NHS figures reveal the number of cancer patients being seen for urgent check-up after GP referral fell to 79,500 in April – a drop of 60 per cent from the previous year. Patients starting treatment for cancer in April fell by 20 per cent from the previous year to 10,800.

Fear of catching the virus has meant that fewer people have been going to their GP with their symptoms. In some parts of the country, cancer referrals dropped by 75 per cent at the peak of the pandemic, as people stayed at home to protect the NHS.

Mesothelioma diagnosis delays

The worry for those of us involved in helping people with asbestos-related diseases such as mesothelioma, is that they too will not approach their GP if they are having symptoms.

People who have been exposed to asbestos in the past might be suffering from asbestos disease symptoms (such as shortness of breath, chest pains, a persistent cough or fatigue) but feel anxious about attending their GP surgery and potentially being exposed to the virus. Others may confuse their symptoms with COVID-19.

It is vital that people who are experiencing mesothelioma symptoms are encouraged to see their doctor as soon as possible. Failing to report symptoms will result in patients not being referred for urgent diagnostics such as X-rays or CT scans, and will mean significant delays to their diagnosis and treatment.

Treatment plan delays

Patients who have already been diagnosed with mesothelioma have experienced delays to their treatment plans. Treatment regimes such as chemotherapy, radiotherapy or surgery have been put on hold temporarily or cancelled indefinitely.

In a recent Mesothelioma UK survey, half of all respondents (50 per cent) reported their treatment schedule had been affected by COVID-19.

Getting a quick and accurate diagnosis and being treated promptly is vital. Any delays could mean that surgical intervention is no longer an option and the effectiveness of certain therapies such as chemotherapy may be affected. In some situations in which diagnosis or treatment has been delayed, patients may be considered too unwell or their cancer has become too advanced to be considered for clinical trials.

Graeme Chisholm, Director at Novum Law

Getting cancer services back on track

The health service has got its work cut out to try and clear the back log of cancer patients waiting for diagnostics and treatment. However, the signs are there that cancer services are starting to get back up and running. Screening programmes are restarting and the numbers of urgent cancer referrals are increasing.

This is welcome news for people yet to be diagnosed with mesothelioma and those who have a diagnosis and are waiting for their treatment to start or resume.

Cancer specialists including lung cancer nurse specialists are working together to coordinate treatment and support, and the NHS is starting to set up ‘cancer hubs’ to help coordinate treatment and ensure it can continue safely.

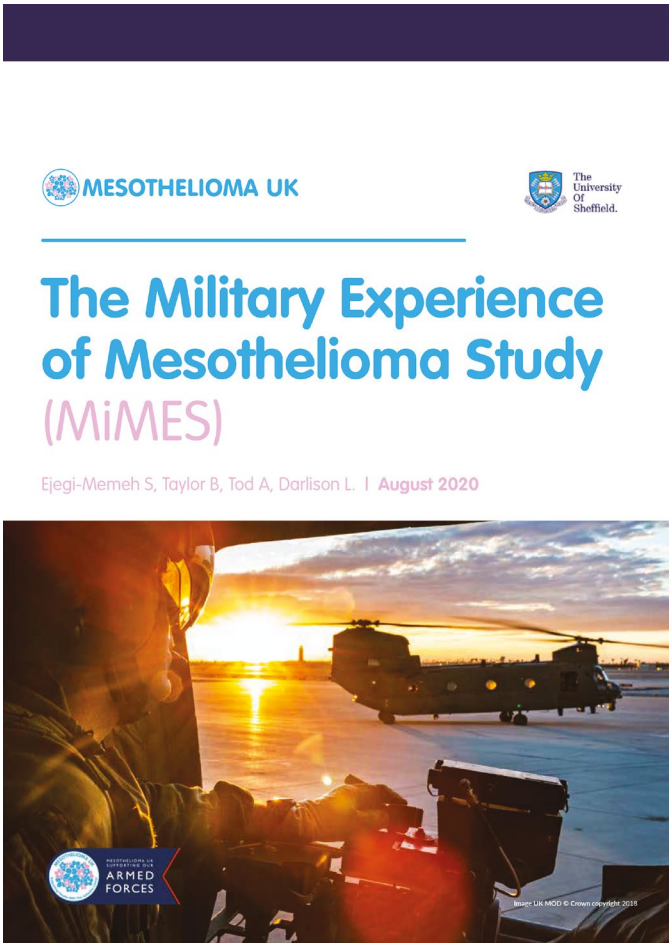
However, there is a long way to go until cancer services are fully up and running and waiting lists are reduced. What may take longer is rebuilding cancer patients’ confidence after months of uncertainty.

If you or a family member has been diagnosed with mesothelioma, our team of specialist asbestos disease solicitors can provide expert legal advice. Call Freephone 0800 884 0777 or email gchisholm@novumlaw.com

ARMED FORCES

Military Mesothelioma Experience Study (MiMES)

MiMES is being conducted as part of the wider 'Mesothelioma UK - Supporting our Armed Forces' initiative. MiMES will help to raise awareness of mesothelioma and establish a comprehensive, shared approach to providing mesothelioma information and support for armed forces personnel and veterans. A team of researchers from the Division of Nursing and Midwifery at the University of Sheffield is undertaking this research.



MiMES aims to understand more about the patient experience of mesothelioma amongst British armed forces veterans. This will help us to understand how to better meet the needs of those at risk of developing the disease and those living with mesothelioma.

We have concluded our interviews with veterans, their family members and relevant staff. We are grateful to all of the people who have taken part in interviews as well as those who have helped with recruitment.

The data has been analysed and a final report has been produced that brings together the interview and national data. Pen portraits are also being developed as educational resources to facilitate care and support of military veterans with mesothelioma.

The final report is available on the Mesothelioma UK website at www.mesothelioma.uk.com/mimes.

Mesothelioma UK ambassador commemorates VJ Day 75 & Battle of Britain anniversary

Members and volunteers of Anglia Asbestos Diseases Support Group commemorated VJ Day 75 and the Battle of Britain 80-year anniversary in the garden of Bury St. Edmunds Farmers Club, courtesy of the club management.

Volunteers enjoyed a buffet lunch and a talk by Mesothelioma UK ambassador, Brian Wallis. Brian focused everyone's thoughts on the 'Forgotten Army' and those who were incarcerated in Japanese POW camps during the months of May-August 1945. He spoke of the exploits of two local heroes who survived their captivity to earn gallantry honours after the war's end.

Brian ended his illustrated talk by reciting the Kohima Address: "When you go home, tell them of us and say – for your tomorrow, we gave our today."

Armed Forces Memorial

The 'Mesothelioma UK – Supporting our Armed Forces' project recently submitted an application to have a dedicated memorial at the National Memorial Arboretum. Initial plans and memorial concepts have been approved by the National Memorial Arboretum steering committee and we are now in the process of raising funds. If this is something that you could support or to find out more, please contact Faye Forde at faye.forde@mesothelioma.uk.com

Mesothelioma UK – Armed Forces merchandise now available!

You can now buy 'Mesothelioma UK – Supporting our Armed Forces' merchandise through the online shop at www.mesothelioma.uk.com/shop/

Recruiting participants for military mesothelioma research project

Virginia Sherborne is working towards a PhD. She has recently completed a review of the research literature about the psychological effects of mesothelioma on patients and their carers, and the review is now available at http://dx.doi.org/10.1002/pon.5454

Virginia's next step is to carry out an interview-based study. This study will explore the psychological effects of mesothelioma from the perspective of carers of UK military veterans with the illness.

From autumn 2020, Virginia will be aiming to remotely interview people who are the main, informal and unpaid supporters of a veteran with mesothelioma. This could include spouses, partners, relatives or close friends.

More information about the study and how to participate will be available on the Mesothelioma UK website soon. Alternatively, please contact the Mesothelioma UK information line on 0800 169 2409 to be part of the study.

FUNDRAISING

Birthday donations

While many of our supporters choose to raise funds for us by running, walking, baking or even sky diving, some have chosen to give up receiving gifts for their special day to support Mesothelioma UK with birthday donations.

Some people choose to ask their friends and family for a donation to us instead of buying them gifts and we're always grateful for their generosity and selflessness.

Recently some of our nurses, the wider team and even relatives of nurses have chosen to do this. In particular, nurse Rachel Thomas, the sister and father of nurse, Helen Wilkes, and Chair of Lung Cancer Nursing UK, Jackie Fenemore, all chose to ask for donations for their birthdays.

Vicky Wilkes said on her Just Giving page that 'it felt right that this contribution should go towards supporting such an important cause when the majority of staff, including my sister Helen, have been pulled away from the charity to work on the front line treating COVID-19 patients.'

Thank you to everyone who supports us in lieu of birthday presents – it means a lot to us as a charity.

If you'd like to help us like this, there are a few ways to do it. You can set up a Just Giving page or if you're on Facebook, you can set up a birthday fundraiser on your page, or you can ask people to donate via our website at www.mesothelioma.uk.com/donate.

Ian Falconer

By Christine Jones
Mesothelioma UK Clinical Nurse Specialist

About a week before the virtual Prudential Race was due to go ahead, I forwarded the details to my brother Ian who had participated in the actual event the year previously! I simply enquired whether or not he would be prepared to attempt the virtual event to help Mesothelioma UK and with no hesitation at all, he told me he would get the bike out and see if he had any chance of covering the distance.

The rest is history. He signed up, organised his GPS tracking and set off round North Ayrshire, although we tracked him round London, a most bizarre situation. He covered the 46kms in just over four hours, surprising even himself and raised a load of money at the same time. I am immensely proud of him and his only criticism of me remains that I could have given him more time to train. Now that sounds like a challenge for the future, Ian...

The power of your pledge

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. Mesothelioma UK has made it our responsibility 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 today.

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, maybe even a cure, and they help to fund our team of mesothelioma nurse specialists and so much more.

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 so we have to carry on the fight against it and you can help us to do that.

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 for your estate and your wishes.

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 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. It's your legacy, your choice...

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

www.mesothelioma.uk.com/pledge

Hannah Smith (Team Smith)

Our dad went to the doctors in May last year with what he thought was a gall stone. Fast forward to June, he was diagnosed with a devastating terminal diagnosis of pleural and peritoneal mesothelioma at the age of 51.

In March, me and seven others decided to challenge ourselves to run a half marathon (The Vitality Big Half) to raise money for Mesothelioma UK. We all completed the race and were cheered on by my dad and family/friends (along with a big Meso UK banner). We raised £6,421.28!!! We were due to do a charity dance show to raise more funds for Mesothelioma UK unfortunately due to the coronavirus, this has been postponed.

Andrew Barton

In May 2020, Andrew Barton opened up a Just Giving page in memory of his father, Terry Barton and asked for family and friends to donate to Mesothelioma UK in lieu of flowers. He raised a wonderful £1,912.50.

"He was diagnosed with mesothelioma in early 2018, a disease caused by working with asbestos during his career as a painter and decorator. After receiving his diagnosis, he approached his life as he always had, in a positive way, setting himself little goals and objectives, carrying on with a normal life as much as he could. He would still walk his dog every day, spend time in Sidmouth, his favourite place after Pelsall, and enjoy his time with his family and friends.

"As time passed, he adjusted his life to deal with the effects of the disease and the extensive treatments he had to endure, and even through all this, knowing that he had a terminal illness, he kept positive throughout, reassuring everyone else at all times along the journey. He will be greatly missed by so many, a man of integrity, warmth, humour and love. The family thought it appropriate to set up this page to allow people to make a small donation, if they so wish, because of the current COVID-19 situation and the reduced funeral service."

Caroline Oanes

Caroline Oanes was due to take part in the Southend Half Marathon on 14 June 2020 in memory of her dad, Anthony (Tony) Hill. Unfortunately, due to COVID-19, the event was cancelled but that didn't deter Caroline.

"I'm still doing this on this date, on my own, for my dad. I had hoped to do this half marathon with dad and the famalam cheering me on in the crowd. We had such plans, but the smaller ones seem to be the ones that hurt more...

"Dad very sadly died at the beginning of February from mesothelioma. This terminal and truly terrible disease comes from those exposed to asbestos. Very little is known about it which is why some people have 10 years and others, like dad, had months to live with from his diagnosis.

"We are all living through tough times with COVID-19, but charities like this one are also trying to find funding to keep up their support and most importantly, fund research to help find a way to prolong life expectancy and hopefully one day, a cure. Anything that we raise here will hopefully help someone one day not have to suffer like our dad did. I do this for you dad, I know you are watching..."

ALWAYS LOVED, NEVER FORGOTTEN.

Lucy Summers

Sadly, on 16 April 2020, my father passed away from mesothelioma, a rare terminal cancer. He was diagnosed last September and underwent radical surgery which we thought may extend his life for up to two years. Unfortunately, dad's health deteriorated and his prognosis was not great.

Mesothelioma UK offers great support to people in need and one of those people was my dad and our family. Dad will always be remembered for his smile and larger than life character. He was a friend to all and will be missed. In his words: "You must live your best life."

In memory of her dad, Lucy raised an incredible £1,637.50 including Gift Aid.

Move for Meso

In May this year, Mesothelioma UK launched its brand-new campaign, Move for Meso. In support of the charity, our patients and carers took on the challenge to virtually raise funds and clock up as many kilometres as you could! In total, our supporters raised an incredible £5,197.38 and travelled 2,029.71 km. Here are just a few of the amazing stories from those who took part:

Natalie Woodward

"I'm Nat, I'm 37, and I was diagnosed with advanced pleural mesothelioma in August 2017. I live and am treated in Spain but I am from Devon, in the UK. I've had continuous chemo since diagnosis and am currently on cycle 45 and am stable.

Mesothelioma UK has helped me from the start of my meso journey with advice and support - as well as supporting all mesowarriors in the UK with their provision of specialist Mesothelioma UK nurses throughout the country, amongst many other things. Personally, and even though I don't live in the UK, Christine, the lovely Mesothelioma UK Specialist Nurse at Derriford Hospital in Plymouth has been a great support to both myself and my parents over the past three years through SWASAG. The yearly Mesothelioma UK Conferences Gonzalo and I have attended for the past two years have been one of our main sources of updated information and contacts. We've had the chance to meet both the top meso specialists and fellow mesowarriors in person which has been invaluable to us both." Natalie exceeded her personal targets of 100km and £1,000 in two weeks. She raised a fantastic £2,367.00 plus £254.56 Gift Aid and reached 111km!

Isobel Grant

"My mum, Christobel Grant of Linlithgow in Scotland, sadly lost her fight with peritoneal mesothelioma on 27 April 2019. We had never heard of meso before and were shocked and devastated when we found out that it was, for her, incurable. From when mum was diagnosed in December 2018 until her death less than five months later, she continued to show the bravery, dignity and humility she had done throughout her 76 years.

We still do not know where she was exposed to the asbestos which cruelly took her life, but suspect it was when she was a radiographer in Kent in the 1960s. How terrifying that this was developing within her throughout this time and that there were no symptoms until a few weeks before her diagnosis. My mum was also a very loving and loved granny, sister and friend, and whilst we are heartbroken that we have lost her to this dreadful illness, we continue to be inspired by her kindness and love, and we know that she would want us to support Mesothelioma UK to raise funds and awareness in her memory."

Isobel raised £128 plus £15 Gift Aid, as well as clocking in an impressive 527 km!

Rowena Bailey & Team Matlock Malpas Meteors against Meso

Rowena Bailey and her team, the Matlock Malpas Meteors against Meso, took part in our campaign and raised a fantastic £102.38 including Gift Aid!

Our Legal Panel Members

Many of our legal panel members were eager to get on board with the Move for Meso campaign. They ran, swam, cycled and even picked up litter on their journeys! We had teams from Irwin Mitchell, Thompsons Solicitors and Royds Withy King, and collectively they raised £1,113.94 (including Gift Aid) and clocked up 1,376 km, an amazing job - well done!

Fieldfisher's Miles for Meso

Some of the team from Fieldfisher took on their own challenge. 'Catching Collier' was a five against one challenge - 'Move for Meso' would be too easy with an ultra-distance runner on the team so it's five against one.

The team really went the distance and the end result was close, but Bridget was pipped to the post by the rest of the team who managed to clock in 468 km with Bridget closely following with 464 km! As well as an impressive amount of mileage they also raised £3,688.75. Huge thanks to the team and everyone who donated!

Team Irwin Mitchell

On 15 March 2020, myself and Kris Inskip planned on running 13.1 miles to fundraise for Mesothelioma UK. Unfortunately, due to the COVID-19 pandemic, we received emails on the morning of the race confirming that it had been cancelled.

Initially the race was put back to October before being re-scheduled for March 2021, but when the virtual event was announced as an option, Kris suggested that we both just go for it...

So here we are! The virtual half marathon took place on 4 July. Kris and I put on our trainers in aid of Mesothelioma UK. Irwin Mitchell's Asbestos Related Disease team sees how mesothelioma (an aggressive treatment-resistant form of cancer caused by asbestos exposure) affects the lives of sufferers and their families.

Mesothelioma UK provides wonderful support, assistance and guidance at an extremely difficult time.

The money raised will help with the research into and treatment of mesothelioma. Money will also go to the amazing doctors and nurses who never give up the fight and always provide hope for those who are suffering from this illness and their families.

Many thanks for your support. Gerry, Katrina, Krysia, Armon, Ed, Holly and Kris!

Specialist lawyers put their best feet forward

Experts from nine Irwin Mitchell offices signed up to take part in a range of activities as part of Mesothelioma UK's latest campaign Move for Meso. The charity's challenge was held across five weeks in June and the start of July, with supporters being encouraged to collectively cover 5,000km by a selection of means including walking, running, jogging, cycling and swimming.

The legal team, which was made up of lawyers from Birmingham, Bristol, Cambridge, Leeds, London, Manchester, Newcastle, Sheffield and Southampton, went on to surpass – and almost double - the target set, covering a distance of more than 9,500km!

This comes after the firm participated in Muffins for Meso earlier this year, with virtual baking sessions and coffee mornings also raising funds for Mesothelioma UK. A total of £1,000 was raised by Irwin Mitchell employees across both events.

Adrian Budgen, Partner at Irwin Mitchell said: "It is fantastic to see our team getting on board with Mesothelioma UK's fund-raising campaigns, especially during what has been a particularly challenging time for charities as a result of the recent pandemic.

"Mesothelioma is a cancer most commonly associated with exposure to asbestos, which has often taken place decades prior to diagnosis. Currently there is no cure for this terrible disease, but the money raised will help Mesothelioma UK continue its important work in researching treatment and providing invaluable support to our clients on a daily basis."

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

Monthly Facebook Q&A with Meso UK Clinical Nurse Specialists plus other healthcare providers
First Tuesday of each month from October 2020, at 11am
www.facebook.com/therealmesouk

Meso Campaigns & Challenges 2020
20 September 2020
20for20 Cancer doesn't stop for Covid
20 Day Challenge

Go Sober in October and support Meso UK.
November is the time that you Grow a Mo or Raise a Brow
www.mesothelioma.uk.com/getting-involved/fundraising

Patient and Carer Day (virtual event)
2 October 2020
www.mesothelioma.uk.com/pcday

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

HUGH | JAMES

NOVUM LAW
NOVUMLAW.COM

fieldfisher

Leigh Day

royds withy king
lawyers ahead of the curve

Slater Gordon
Lawyers

IM irwinmitchell

THOMPSONS SOLICITORS
STANDING UP FOR YOU

www.mesothelioma.uk.com | Produced by Sandstar Communications and Foil Design | **ISSN 2632-9972**