MESOTHELIOMA MATTERS

October 2018

Patient and Carer Day 2018

New Grants and Trusts Fundraiser

First place for RHS garden

Liam's cycle challenge

MESOTHELIOMA UK
Supporting People With This Asbestos Cancer

PATIENT AND CARER DAY 2018 & RACE NIGHT

Save the date! Meso UK will be hosting the 13th annual Patient and Carer Day for people with mesothelioma and their families, friends and carers. It's a day of learning, sharing experiences and meeting others in similar situations (and it's free for patients and their families).

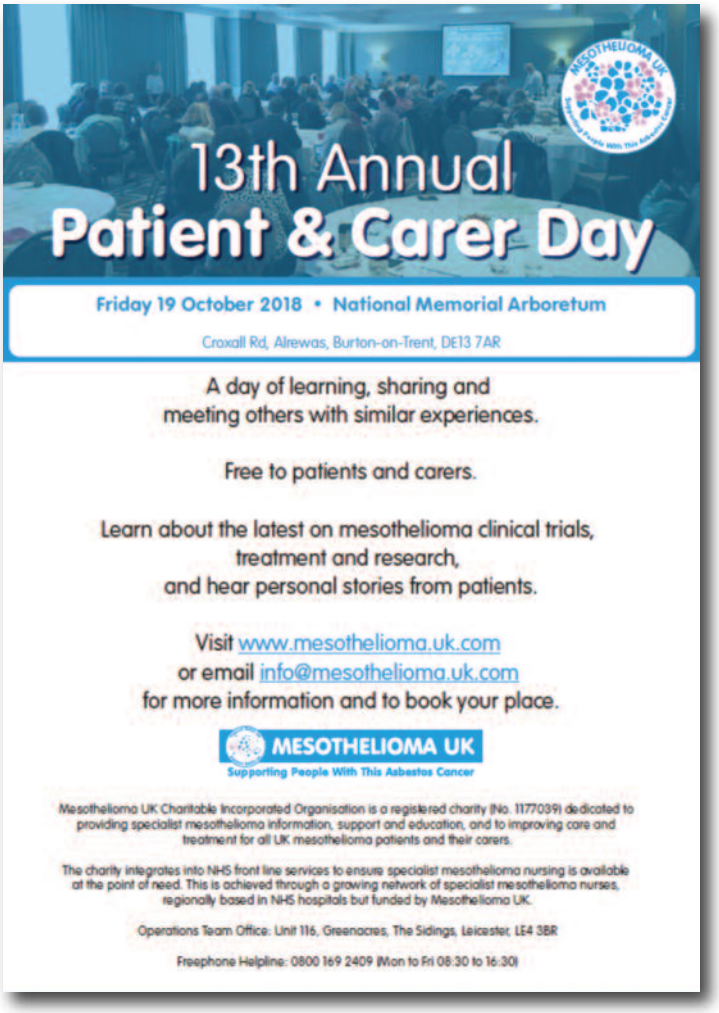
When: Friday 19 October 2018
Where: The National Memorial Arboretum, Burton-on-Trent, DE13 7AR

Guest speakers will include oncology consultants, clinical nurse specialists, researchers, patients and support group founders.

We're also hosting 'Celebrating Mesothelioma UK – a Night at the Races'.
When: Thursday 18 October
Where: The National Memorial Arboretum, Burton-on-Trent, DE13 7AR

This promises to be a fun night with six races, a three-course meal and a small awards ceremony. Tickets are £60 per person for individuals and charities, or £750 for a table of 10, for corporate organisations.

Please email info@mesothelioma.uk.com or visit www.mesothelioma.uk.com to find out more, or book your place at either event. For corporate enquiries, please contact Jill Lemon on 0800 169 2409 or via email at jill.lemon@mesothelioma.uk.com



NEW BUSINESS MANAGER JOINS

Mesothelioma UK has appointed Faye Forde as its new Business Manager. Faye will work with the charity's seven-strong Operations Team to manage its business operations and help it to achieve its business goals.

Faye's responsibilities will include streamlining the internal systems and processes, managing the workload of the teams, and ensuring the charity is compliant and working in accordance with best practice for Charity Governance Code. She will also work to recruit new trustees, volunteers and interns.

Before joining Mesothelioma UK, Faye worked as an Operations Manager for a visual communications company. Faye brings previous experience in office and operational management to her new role and has also previously worked in retail management.

Faye Forde commented: "I've always wanted to work in the non-profit sector. I have a drive to help others and contribute to something that has a real, positive impact on people. Mesothelioma UK does some amazing work and makes a difference to people and I'm looking forward to being part of that."

MESOBANK MILESTONES

- MesobanK recruited its 500th donor in July this year
- To date, 22 research groups have applied to MesobanK for a supply of tissue for use in research investigating the causes, development and /or treatment of asbestos related diseases
- As well as biological samples and data, they are also looking to collect and store radiological images (CT Scans) from donors that are undertaken as part of their routine care
- The REC approval for the Tissue Bank was renewed for a further five years in August
- During the month of September, adverts will be running for the BLF Mesothelioma Research Fellowship Programme. They are looking to appoint a Clinical Research Fellow and/or postdoctoral researcher to undertake research in a field related to malignant pleural mesothelioma.

DONATE AS YOU SHOP ON AMAZON

AmazonSmile is a simple and automatic way for you to support Mesothelioma UK every time you shop, at no cost to you.

When you shop at smile.amazon.co.uk, you'll find the exact same low prices, vast selection and convenient shopping experience as amazon.co.uk, with the added bonus that Amazon will donate a portion of the purchase price to your selected charity.

Learn more about AmazonSmile and start supporting Mesothelioma UK via your Amazon shopping today.

www.smile.amazon.co.uk

OVER £3.4 MILLION IN CLAIMS

Caroline Barry is Mesothelioma UK's Benefits Advisor. In the 2017/18 financial year, Caroline supported 178 patients and carers to make claims for benefits and state compensation, helping them to access over £3.4 million in lump sum payments and benefits.

If you have been diagnosed with mesothelioma, there are certain benefits that you may be able to claim along with a government lump sum compensation.

You have a legal entitlement to some of these benefits and they are not all affected by your level of household income or savings.

Caroline is there to help you to identify to which benefits you are entitled and to help you to apply for them.

There are also lots of leaflets on our website on the different benefits available. For help with benefits claims, please call our helpline on 0800 1692409 or email info@mesothelioma.uk.com

FUNDING FOR RESEARCH STUDIES

Dr Catherine Henshall

Karen Lord

Mesothelioma UK is committed to supporting research into all aspects of treatment and care related to mesothelioma.

Each year, we work with the National Lung Cancer Forum for Nurses (NLCFN) to make funding available for NLCFN members to undertake a small-scale research study, a complex audit or a preliminary enquiry to support a larger grant application.

This year we have funded two studies, one of which will be carried out by our Clinical Nurse Specialist Karen Lord.

Living well with mesothelioma
Karen will conduct a national study to generate evidence-based recommendations for 'living well' with mesothelioma, using the views of patients and family carers, and the observations of health professionals.

How to 'live well' with long term conditions such as cancer is a priority of UK government. However, little research exists to help us understand what 'living well' means to people with mesothelioma and their families.

Karen's study will involve interviews with patients to identify any common themes around what constitutes living well. Studies involving patients with other long-term conditions have highlighted patients' need for self-esteem, and reliable professional and peer support, retaining personal responsibility and preserving identity.

The study will investigate if these findings apply to mesothelioma patients or if there are unique factors that enable them to live well.

The qualitative study will consist of two stages:
- Individual interviews with patients and family carers
- Two focus groups to verify and expand on the findings

The findings will be used to produce a guide to living well with mesothelioma used for patients, carers in the design of patient information.

Best practice for follow up care
The second study is research into improving follow up care for UK patients with mesothelioma.

The recipient of the grant is Dr Catherine Henshall, Senior Nursing Research Fellow at Oxford Brookes University, who will carry out a study to identify best practice for patient follow-up care.

Dr Henshall's new study will explore mesothelioma patients' experience of follow-up care in three NHS trusts.

Five interlinked objectives will aim to gain an understanding of current follow-up care pathways, examine patient experience of follow-up, identify patterns between treatment types received, compare findings across the trusts to identify commonalities and differences, and to propose a revised, patient-focused follow-up care service that places patient experience at its heart.

Commenting on the study, Dr Henshall said: "We are delighted to have received this funding from Mesothelioma UK and the NLCFN which will enable us to explore mesothelioma patients' experiences of follow-up care.

"This will enable us to make informed recommendations for policy and practice, and to propose preferred, patient focused, follow-up services that are evidence-based, collaborative and inclusive.

"We are committed to working closely and in partnership with Mesothelioma UK throughout this project to ensure that the best outcomes for mesothelioma patients are identified and promoted, and to make a real and lasting difference to mesothelioma patient care and service delivery."

Liz Darlison, Mesothelioma UK Head of Services said: "Mesothelioma UK is delighted to continue working in partnership with the NLCFN Research Interest Group to provide annual grants that support nurse-led mesothelioma research.

"We are grateful to the charity's supporters whose valuable contributions make this possible. These studies will provide very useful clinical evidence to influence care and services. We wish Karen and Dr Henshall every success and look forward to helping to evaluate and disseminate findings in due course."

ACTION MESOTHELIOMA DAY 2018

Each year in July we are overwhelmed by the number of Action Mesothelioma Day events that take place around the country. While we wish the day wasn't necessary, it's encouraging to see so many events as it means awareness of mesothelioma is increasing.

In Leicester, where Mesothelioma UK is based, we held a service of reflection and hope at Leicester Cathedral. Patients, families, friends and healthcare professionals gathered to hear talks, share stories and pay tribute to those they have lost to mesothelioma.

Thank you to everyone who organises or supports an Action Mesothelioma Day around the UK.

COMPENSATION CLAIM – JACKIE'S EXPERIENCE

I have just read the Mesothelioma Matters Magazine and feel I need to share my story with you.

My late husband, Kevin Scott, was diagnosed with mesothelioma in 2012, when he had just turned 61 years of age. It was a total shock to us and during this time we never really took it in properly. We both tried to be as unemotional as possible and never really discussed Kevin's diagnosis. We were worried for each other and tried to simply get on with our lives as best we could, whilst knowing that there was no cure.

We had no choice but to live each day as it came.

Kevin found it hard to tell his mother about his mesothelioma, as it was his father who had secured him a holiday job in the same factory where he worked. It was in this factory while dry sweeping and cleaning that Kevin contracted mesothelioma. Kevin's reluctance to tell his mother came simply from a position of compassion as he did not want to upset her, as he knew that she would blame herself for allowing him to take the job.

When the time turned to considering whether to pursue a mesothelioma compensation claim, Kevin felt it would be too distressing and accepted the Government's low compensation offer. In hindsight, this was very foolish, but Kevin didn't want his final months with his family overshadowed by a very distressing process and possible court fight.

After my husband had died I found myself struggling to cope with the loss. Added to this my daughter had just recently had a baby and as they lived abroad I was only able to spend weeks at a time with her. I tried to forget what had happened to Kevin, but in the back of my mind, I needed closure.

I did have concerns about Kevin's treatment and the way he had been dealt with. I decided to meet with the hospital staff in order to better understand the level of care that Kevin was afforded and the lines of communications that were in place between the hospital staff and Kevin during his last months.

I also felt justified in pursuing the compensation claim that was open to Kevin and understood that there was a three-year limitation period after Kevin's death to bring this.

What came as a huge shock was that due to the fact Kevin was reluctant during his last months to spend time providing detailed witness statements and recounting every detail about the time he spent in the factory and the associated levels of dust which he encountered, the solicitors advised me that due to the lack of evidence in Kevin's witness statement, that they were unwilling to take the compensation claim forward on a no win no fee basis. This meant that my only option was a costly court case.

I have recently been introduced to two ladies whose husbands also died of this horrific disease. Their husbands, however, managed the mesothelioma claim themselves and whilst I appreciate the reasons why, it has left me with a lot of mixed emotions...namely that Kevin didn't matter. I feel that I have let my husband down, that I was not strong enough to fight for him and worst of all, that Kevin was simply just another statistic.

I do think things are improving slowly, more nurses and dedicated professionals are available and there is better help for people going through this. However, what I cannot reconcile is the lack of guidance with respect to making a compensation claim. While I am not a financially-driven person, it is important that people who are in a less fortunate position than I am realise that solicitors and associated parties will require detailed accounts / witness statements, all of this information is vitally important. It is true that going through this process is the last thing that you will want to do when all of your strength and focus is on your loved one, but as somebody who did not push hard enough or provide the level of detail required, I wish somebody had of taken me by the hand and stressed the importance of this to me and Kevin.

I have found my conversations with the two ladies who have experienced what I am going through helpful. My friends simply do not understand what it is like to lose a loved one in these awful circumstances, let alone your husband.

I hope by writing this letter that it may in some small way help others in the future going through this and allow them to understand that we are not alone!

ADVICE FROM MESOTHELIOMA UK TRUSTEE AND PARTNER AT IRWIN MITCHELL SOLICITORS:

The situation in which Mrs Scott found herself after she lost her husband is sadly all too common. When the person diagnosed with mesothelioma dies, the account of how, when and where he / she was exposed to asbestos is often lost. In the absence of a description of how exposure occurred, it becomes much more difficult to prove that the exposure to asbestos was negligent. I would urge everyone with a diagnosis of mesothelioma to seek expert legal advice and at least consult an experienced solicitor, who will be pleased to prepare a detailed statement to record the vital evidence of how you were exposed to asbestos.

This consultation and statement preparation should be free of charge and there will be no pressure on you to take legal proceedings. Your story of asbestos exposure will be preserved, just in case at some time in the future you or your loved ones change your minds. Strict time limits also apply. Court proceedings must be started within three years of diagnosis, or within three years of someone having passed away due to the illness (if within three years of diagnosis). There are some instances where the court can use its discretion to dis-apply the time limit, but this cannot be guaranteed.

Information which you provide to the DWP for IIDB is not the same as providing a signed statement of your exposure to a solicitor. The DWP requires much less detailed information.

NEW GRANTS AND TRUSTS FUNDRAISER AT MESO UK

Ian Poynton has joined Mesothelioma UK as Grants and Trusts Fundraiser. Ian will be based at the charity's Leicester headquarters and will work closely with the Fundraising Manager to help to increase the charity's income, focusing on grants and trusts.

Ian has nine years' experience of working in the National Governing Body and charity sector in a variety of roles from club development, marketing and communications, to fundraising. He joins Mesothelioma UK from British Wheelchair Basketball where he secured funding for new programmes. Before that, he was Grants Manager for Sport England.

Ian commented: "I really wanted to use my experience of fundraising, and my skills and influence to help a charity which offers real support and hope to others. Mesothelioma UK relies solely on donations so fundraising is vitally important."

Liz Darlison, Mesothelioma UK Head of Services, said: "We are delighted to welcome Ian to the Mesothelioma UK Operational Team. Ian is keen to learn more about mesothelioma and can see what a worthwhile organisation he has joined.

"He is looking forward to meeting all of the Meso UK community, especially patients and their families, and will help us to achieve our fundraising goals that are vital to funding specialist nurses, clinical research, and treatment for mesothelioma patients and their families," continued Liz.

FIRST PLACE FOR MESOTHELIOMA UK AT HAMPTON COURT FLOWER SHOW

Mesothelioma UK was awarded £4,000 after receiving the most public votes for its charity garden at the Royal Horticultural Society's Hampton Court Palace Flower Show.

TV gardener David Domoney was commissioned by home improvement company Everest, to design three charity gardens at the show. TV personality, Carol Klein, nominated Mesothelioma UK as one of the charities and each of the garden displays was designed to reflect the charities.

Visitors to the show and fans on social media voted for their favourite front garden display, with almost 2,500 votes cast in total. Mesothelioma UK was the clear winner with nearly 1,700 votes and received a £4,000 donation from Everest.

Some team members went along to see the beautiful garden which showed a direct contrast between its two sides, with the design reflecting the support that Mesothelioma UK brings to those suffering, specifically those in the merchant navy. A circular border of planting and engraved forget-me-nots, the symbol of Mesothelioma UK, remind people to think of this cancer and the dedicated nurses that the charity provides.

David Domoney commented: "I wanted to capture two sides of life, one symbolising the passing of time without illness, using a curved path to give you the longest route. The other, representing illness, suggests the moments of peace and tranquillity that life gives us among its challenges. All gardens can stir emotions and help us to appreciate the value of life while we are close to nature."

Liz Darlison, Head of Services at Mesothelioma UK, said: David's design captured the impact so well; it was a design to which we could all relate and one that we would all love to replicate in our own gardens.

"We feel so honoured to have our garden voted for by the public. The fight against mesothelioma is a particularly worthy cause as it's a quiet public health disaster, causing unnecessary devastation on a large scale.

"Many thanks to David, Everest and Carol Klein for their support, and to everyone who voted. It's much appreciated by UK patients and their families."

The £4,000 donation will be used to support the charity's ongoing work, which includes staffing a helpline service for patients, raising awareness of mesothelioma, providing treatment for patients, paying for Mesothelioma Clinical Nurse Specialist posts around the UK, and funding research and clinical trials into the disease.

SUPPORTING OUR ARMED FORCES

MESOTHELIOMA UK SUPPORTING OUR ARMED FORCES

Our new service – Supporting Our Armed Forces – is doing well and we are engaging with an increasing number of organisations to pool our resources and reach out to those veterans and armed forces personnel who need our support.

One such organisation is the Veterans' Outreach Support (VOS). Founded in July 2008 after a Falklands pilgrimage, VOS began as an informal volunteer support group based in Portsmouth. The founding members, themselves Falklands veterans and family members, wanted to create a welcoming environment for service veterans where they could access a range of support services. Now a registered charity, VOS has grown in expertise, capability and capacity, and is funded by a number of generous national military charities to deliver its invaluable service to veterans and their families across Hampshire and beyond.

Today, the monthly VOS Drop-In provides a welcoming and relaxed place where UK veterans and family members can come for confidential welfare advocacy or psychological support, or simply to meet socially. It is a unique meld of public, private and charity sectors offering one-stop assistance including legal, housing, financial, employment, spiritual, alcohol and mental health support.

Mesothelioma UK is joining the list of agencies offering our support to those attending the drop-in session and we hope to reach many veterans to raise awareness of mesothelioma and the help that's available.

We are also attending some Armed Forces and Veterans Breakfast Club meetings around the country.

Our private Facebook group is available for members to chat and share experiences. We also post relevant news and information on there.

www.facebook.com/groups/mesoUKarmedforces

MILITARY MESOTHELIOMA EXPERIENCE STUDY (MIMES)

By Angela Tod and Beth Taylor, University of Sheffield

The MIMES research study is being conducted as part of the wider Mesothelioma UK - Supporting Our Armed Forces initiative.

Mesothelioma UK - Supporting Our Armed Forces aims to raise awareness of the disease and establish a comprehensive, shared approach to providing mesothelioma information and support for armed forces personnel and veterans.

The incidence of mesothelioma amongst UK military personnel is not known. It is important to understand more about the patient experience of mesothelioma amongst British armed forces personnel/veterans. This will help us to understand how to better meet the needs of those at risk of developing the disease, and those newly diagnosed.

The School of Nursing and Midwifery at the University of Sheffield is conducting some research to explore the experiences of British Armed Forces personnel/veterans with mesothelioma and their family members. This research will engage with health professionals and support agencies to identify how services can best meet the health and support needs of these patients and their families.

Progress so far with MIMES:

1. We have appointed a PhD student to conduct some additional research linked to patient / family carer experience. The student will start in October 2018. Further details of the exact study will follow

2. Research ethics committee approval has been awarded for the main study

3. Data collection and initial interviews will commence in October

RAISING AWARENESS OF OUR ARMED FORCES PROJECT

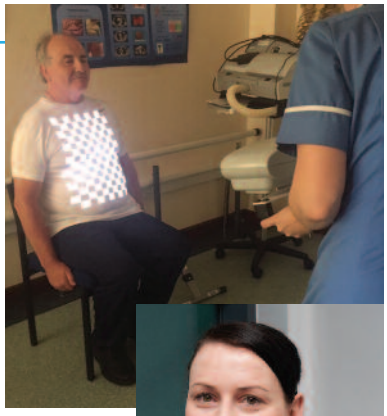
Brian Wallis, Mesothelioma UK Ambassador, together with volunteer members of Anglia Asbestos Diseases Support Groups (AADSG) have been busy during July and August, promoting Mesothelioma UK, and in particular, our Armed Forces project.

The group distributed over 800 leaflets at various military and veterans' events to veterans and senior medical/health and safety representatives at a range of events and meetings.

Brian, Eileen and Joseph recently attended events at the Imperial War Museum in London, the IWM Duxford in Cambridgeshire and the RAF Museum in Hendon, Middlesex. They also visited the medical facilities at RAF Coningsby, Lincolnshire, at RAF Marham, Norfolk and the Royal Engineers Heritage Centre at Waterbeach Barracks, Cambridgeshire. Further visits to military/veterans' facilities are planned for September through to November.

Brian has military connections going back at least four generations and himself served as a Logistics Officer with the MoD before retiring in 1996. His late wife Rosemary was also a Crown employee, before her untimely and tragic death from mesothelioma in 2013.

NON-INVASIVE DIAGNOSIS STUDY



Last year Pat Stone Meso Support and Mesothelioma UK awarded a grant for a study that aimed to reduce the need for diagnostic surgery.

The grant, for £21,795, was awarded to Amy Kerr, Senior thoracic surgery research nurse at the Medical Innovation Development Research Unit (MIDRU) at Heartlands Hospital in Birmingham. The study looked into non-invasive diagnosis of mesothelioma using structured light plethysmography (SLP).

SLP is a new diagnosis method which measures chest wall motion which can highlight differences according to the disease that is causing abnormalities on chest X rays or CT scans.

Integrating SLP into future clinical practice to diagnose mesothelioma could improve the diagnostic process for patients with possible mesothelioma and reduce the need for hospital admission for invasive investigations.

It could reduce the length of time patients have to wait for a diagnosis and it offers patients, who are not well enough to have surgery, a more confident diagnosis for their pleural disease which could help provide evidence for compensation claims.

The study recruited 75 patients and all patients have undergone their planned surgical procedure. Patients were positive about contributing towards research and the recruitment rate was very high. There have been no adverse events related to the study.

A small number of patients are still to complete follow-up but provisional results have been submitted for presentation at the World Conference on Lung Cancer in Toronto, Canada in September 2018.

Amy and the research team are looking forward to being able to present the full results and submit them for publication to share the findings with clinicians and the public.

RECIPE: AUTUMN SAUSAGE CASSEROLE

By Victoria Driver, Oncology Specialist Dietitian

With autumn quickly approaching here's a warm, comforting dish. This easy, one pot sausage casserole, packed with flavours, is sure to be a family favourite.

Ingredients

2 tbsp olive or rapeseed oil
I onion finely chopped
2 medium sticks celery, finely chopped
1 yellow pepper, chopped
1 red pepper, chopped
3 fat garlic cloves, chopped
chorizo sausage (about 400g)
6 pork sausages (about 400g)
1½ tsp sweet smoked paprika
½ tsp ground cumin
1 tbsp dried thyme
125ml white wine
2 x 400g tins cherry tomatoes or chopped tomatoes
2 sprigs fresh thyme
1 chicken stock cube
1 x 400g tin aduki beans*, drained and rinsed
1 bunch chives (optional)

*Aduki beans are tiny, reddish-brown beans with a cream coloured seam and sweet, nutty flavour. They have more calories, protein, vitamins and fibre than kidney beans but if you are struggling to find them in your supermarket, kidney beans are suitable alternative

Method

1. Heat the olive or rapeseed oil in a large heavy-based pan. Add the onion and cook gently for 5 minutes. Add the celery and peppers and cook for a further 5 mins.

2. Add the sausage and chorizo and fry for 5 minutes, then stir in the garlic, spices and dried thyme and continue cooking for 1 – 2 mins or until the aromas are released.

3. Pour in the wine and use a wooden spoon to remove any residue stuck to the pan. Add the tinned tomatoes, and fresh thyme and bring to a simmer. Crumble in the stock cube and stir in.

4. Cook for 40 minutes. Stir in the beans and cook for a further five minutes. Remove the thyme sprigs, season with black pepper.

Serve with mashed or jacket potatoes, pasta or if you want to keep it easy just serve with bread and butter. Remember to use plenty of butter and cream in your potatoes if you have a poor appetite.

NLCFN ANNUAL CONFERENCE

The National Lung Cancer Forum for Nurses (NLCFN) is hosting its annual conference in November for healthcare professionals. The day offers delegates the chance to recharge their batteries by interacting with like-minded colleagues and learning from the experts about the latest developments and treatments in lung cancer.

Some members of the Mesothelioma UK team will be attending the conference that will also explore the challenges and threats that healthcare professionals are working under and look at new ways of working with patients and colleagues in a changing landscape.

www.nlcfn.org.uk/annual-conference

CLAIR CREATES LEGACY FOR HUSBAND, BRIAN

Since losing her husband, Brian, to mesothelioma, Clair York has been working hard to ensure that he leaves a legacy to benefit others.

Brian York, a former PE teacher, died in December 2015. He was 63 and had been an inpatient at St Wilfrid's Hospice, Eastbourne, for about two months before his death. The hospice has now received £12,022.55 from specialist asbestos lawyers, Irwin Mitchell as part of a legal case after Brian was exposed to asbestos whilst working as a PE teacher and head of year at Imberhorne School, in East Grinstead.

Irwin Mitchell acted on behalf of Clair, 61, to secure the substantial sum in relation to the cost of Brian's care at St Wilfrid's Hospice.

The funds recovered on behalf of the hospice follow a landmark ruling in a 2010 case, led by Irwin Mitchell, that ruled that the insurers of a company responsible for the death of a worker from an asbestos-related disease should contribute to the cost of the care provided to the victim, by their hospice.

Clair, a former teacher, said: "The staff at St Wilfrid's provided invaluable support at a time when we needed it most.

"Brian really wanted to ensure that the hospice recovered its costs as both of us felt so strongly that it should be rewarded for all of its hard work and dedication."

In addition to the donation, Clair volunteers at the hospice as a ward clerk on a regular basis and has taken part in sponsored events to raise funds to support St Wilfrid's.

Colin Twomey, from St Wilfrid's added: ''St Wilfrid's hospice is incredibly grateful to Clair, who has spent so much time and energy making it possible for the hospice to receive the fantastic sum of over £12,000 which enables us to care for more patients and get closer to more people who are at the end of life."

Clair has also worked alongside the Hampshire Asbestos Support and Awareness Group (HASAG) to launch a monthly coffee morning support group at the Civic Centre in Uckfield.

HASAG provides free support, guidance and information to people with asbestos diseases and the charity runs regular coffee mornings across the South of England, South East, London and Home Counties.

Mesothelioma UK welcomes each and every donation that seeks to improve the treatment of and support for mesothelioma patients and their families. If you want to donate directly to the charity to help to support clinical research and fund our UK nurses, please visit www.mesothelioma.uk.com/getting-involved/donate/

SUPPORT GROUPS MEET WITH MAVIS ROBINSON, MBE

John Flanagan from Merseyside Asbestos Victims Support Group (MAVS) and Paula Walker from South Yorkshire Asbestos Victims Support Group (SARAG), recently met with Mavis Robinson MBE, founder of the Mesothelioma Information Project which formed the foundation of what became Mesothelioma UK.

Mavis, who is now retired and living near Leeds, previously worked as a Macmillan Nursing Sister both in the community and in hospitals in the city. From the 1980s and 1990s, Mavis began to see more and more people diagnosed with mesothelioma, not least because of the asbestos exposure suffered by communities living or working at the J.W Roberts asbestos textile factory in Armley, Leeds, for example. This included the late June Hancock who developed mesothelioma after exposure to the mounds of asbestos exuded by the Roberts factory into the nearby school playground and surrounding streets.

In response to the growing numbers of people diagnosed, and because information about the asbestos cancer was so little known and difficult to find, Mavis compiled a booklet to give basic information and guidance on mesothelioma for people with the disease, their carers, their families and health professionals. More than that, in 1997, she founded the UK-wide Mesothelioma Information Project which provided a telephone helpline, staffed by Mavis, to give information and support to sufferers, their families and carers, and information to health professionals.

As part of the Mesothelioma Information Project, Mavis also developed and delivered specialist training for the many lung cancer nurse specialists based throughout the UK on health care, diagnosis, clinical research, palliative care and medical treatment. In 2000, Mavis was invited as a keynote speaker to the first-ever Global Asbestos Conference in Brazil, giving a presentation about her Mesothelioma Project to international medical professionals and colleagues.

In 2002, her outstanding work and dedication was deservedly recognised with an award of an MBE. After Mavis retired, the Mesothelioma Information Project moved to Glenfield Hospital in Leicester and eventually developed as Mesothelioma UK. If any old friends or colleagues would like to catch up with Mavis, please contact MAVSG on 0151 236 1895 or SARAG on 01709 360 672 for contact details.

John Flanagan from MAVS with Mavis Robinson MBE (centre), and Paula Walker from SARAG.

NEW ARTIFICIAL INTELLIGENCE TECHNOLOGY TO MEASURE MESOTHELIOMA TUMOURS

Dr. Kevin Blythe, of the University of Glasgow, is working with a medical technology firm in Edinburgh on a project that aims to develop innovative ways of tackling mesothelioma.

The imaging specialists, Canon Medical Research Europe, has been awarded £140,000 funding to work with mesothelioma specialists at NHS Greater Glasgow and Clyde to develop a prototype that will focus on the assessment and measurement of tumours, which can be difficult in the case of mesothelioma, due to the unusual shape of the tumours.

The project aims to develop technology that rapidly and accurately measures the size of mesothelioma tumours and will use data gathered from previous studies to train computers to identify areas of images that contain tumours. The technology could save time and money in the diagnosis and treatment of the disease.

BRINGING TOGETHER THE MESOTHELIOMA RESEARCH NETWORK

By British Lung Foundation (BLF)

The BLF's Mesothelioma Research Network (MRN) brings together researchers working on mesothelioma. It helps them to share ideas and support each other, and to get better results faster. We hope that it will mean that researchers' great ideas can be more quickly translated into new ways of diagnosing and treating people with mesothelioma.

In June, we held the first ever MRN Research Day, which 85 researchers attended. The aim of the meeting was to give attendees an overview of the different research studies being carried out and to learn about best practice for caring for people with mesothelioma. We were very lucky to have a great line up of speakers, who are leaders in their field, from all over the UK.

Unique to this event was the chance for people doing their research in a laboratory to connect with researchers who are healthcare professionals, who carry out their research with patients. The meeting provided crucial opportunities to network, which will encourage more research collaboration. A number of early career researchers used the opportunity to present their newest data, either by giving a talk or bringing along a poster.

Delegate feedback from the event was very positive. 85% of those that returned an evaluation form felt the programme was excellent or good, half felt they'd made contacts that could form new research collaborations and 86% felt that the event would have an impact on their research work or clinical practice going forward.

You can find out more by visiting the BLF website and reading our blog about the day www.blf.org.uk/your-stories/meso-research-day. If you are professional and work in mesothelioma research, please visit www.blf.org.uk/mrn to join our research network.

UK MESOTHELIOMA ALLIANCE UPDATE

By UKMA Chair, Dawn Mckinley

The UK Mesothelioma Alliance (UKMA) was established in 2017 to bring together mesothelioma stakeholders as one voice to raise awareness of mesothelioma through agreed projects.

The first project that the UKMA is leading is the development of a Service Specification and Optimal Pathway for Mesothelioma, similar to that recently developed for NHS England by its Lung Cancer Clinical Expert Group (CEG). The CEG has given its support to this.

Professor Michael Peake chairs this development group which includes representatives from the CEG, clinicians and other Multi-Disciplinary Team (MDT) members and advocates. The development group first met in April 2018 to discuss the first draft of the Service Specification, produced by Professor Peake, and since then, the group has developed it further to the ninth version.

Professor Peake has opened discussions with NHS England and recently met with the London Specialised Commissioning team and discussions are on-going. The UKMA's hope and ambition is for the Service Specification and Optimal Pathway for Mesothelioma to be adopted and implemented by NHS England as it believes that this is a vital step to equitable access to care and treatment for mesothelioma patients.

www.ukmesoalliance.org

MESOTHELIOMA UK ALLIANCE

UPDATE FROM THE INTERNATIONAL BAN ASBESTOS SECRETARIAT

Edited content taken from the British Asbestos Newsletter by Laurie Kazan-Allan

The annual Parliamentary Asbestos Seminar took place on 26 June, 2018 at the House of Commons. The event offered the opportunity for Members of Parliament to hear about a diverse range of global asbestos developments.

MPs in attendance included Jo Stevens, Chair of the Asbestos Sub-Committee, Labour Shadow Secretary of State for Work and Pensions Margaret Greenwood MP, London MP Stephen Timms (Labour), West Dunbartonshire MP Martin Docherty-Hughes (Scottish National Party), representatives of Bath MP Wera Hobhouse (Liberal Democrat) and others. Also in attendance were dozens of campaigners from asbestos victim support groups, asbestos charities, trade unions and non-governmental organisations.

The first speaker was Sir Anthony Newman-Taylor, Professor of Occupational and Environmental Medicine, National Lung and Heart Institute, Imperial College and Chair of the Scientific Advisory Board of the National Centre for Mesothelioma Research (NCMR). He talked about research at the Centre into understanding mesothelioma as a basis for developing a treatment that could, in the long term, convert this fatal cancer into a manageable chronic condition.

Jason Addy presented on the issue of asbestos-contaminated land. Local people in Spodden Valley, Rochdale have been engaged in a 15 year campaign to ensure that the site of the former Turner Brothers Asbestos factory – the world's first and largest asbestos complex – was scrutinised, tested and remediated in a transparent manner so that safe decisions could be made about its future. Tens of thousands of tonnes of asbestos waste remained under the huge site, with soil and water contamination a potent threat to the health of people who lived or worked nearby. Photographs shown by Mr. Addy of child trespassers in the abandoned T&N asbestos factory caused gasps from members of the audience.

The keynote presentation was given by Fernanda Giannasi, Civil, Health and Safety Engineer, Retired Labour Inspector and Co-Founder of Associação Brasileira dos Expostos ao Amianto (ABREA) [Brazilian Association of the Asbestos-Exposed]. She explained that, while several of the country's 26 states had acted unilaterally and banned the processing, use and sale of asbestos and goods containing it, it was a verdict by the country's Supreme Court last year that finally sounded the death knell for this formerly powerful industry. The Court's decision that declared the federal government's policy allowing the controlled use of asbestos unconstitutional, was binding in all Brazilian states.

However, despite public and judicial support for asbestos prohibitions, an injunction unilaterally issued on 20 December, 2017 by Supreme Court Justice Rose Weber suspended the asbestos ban in states that had not yet enacted prohibitions until all appeals had run their course.

John McClean, head of the Asbestos in Schools Group (AiS) then talked about the slow progress being made as a result of negotiations between the AiS and the Department of Education's (DfE) Asbestos Steering Group. Outcomes include guidance for schools and questionnaires and surveys about the state of asbestos in schools across England and Wales. Compliance with requests for information from schools is voluntary but the Health and Safety Executive (HSE) has agreed to undertake a proactive pilot inspection of 50 schools this autumn.

Commenting on the event, Chair Jo Stevens said: "The seminar showed that, despite asbestos having been banned in Britain for almost 20 years, there is still a huge problem out there. Millions of tonnes of asbestos are still in place in workplaces across the country and every year 5,000 people die prematurely because of past exposure.

"Two things were very clear from the seminar. The first was the huge energy there is out there to make sure that these victims are supported and this terrible killer fibre eradicated. The second is the need to support those who are fighting in other parts of the world against the asbestos industry to try to secure an asbestos-free world."

ASBESTOS DISEASE CASES PROGRESSED IN THE HIGH COURT

By Annabelle Neilson, Senior Associate Solicitor, Boyes Turner LLP

On 13 June 2018, the High Court held an Asbestos Court Users meeting. The meeting was chaired by Senior Master Fontaine with significant contributions from Master Davison, Master Eastman, Master McCloud, Master Thornett and Master Gidden. Dedicated Masters oversee the swift progression of each and every asbestos disease case. Mesothelioma claims are prioritised and, using the dedicated asbestos list at the High Court, legal representatives can progress mesothelioma cases to trial within the lifetime of the sufferer.

Another way in which the High Court supports the needs of asbestos-related disease sufferers is by encouraging the parties' legal representatives to make use of the 'show cause' procedure. By doing so, the court can identify swiftly those cases where liability is in dispute or where judgment on liability can be entered and the claim progressed quickly to an assessment of damages hearing.

The Masters highlighted their expectation that by the first case management conference both the claimant and defendant must know where they stand in relation to a show cause hearing. If there is a simple, short point in dispute then this can be dealt with at the first 30-minute hearing. More complicated issues will require a longer hearing at a later date and the claimant and defendant are expected to provide for this in their directions.

The Masters clarified that all asbestos cases (not only mesothelioma claims) are appropriate for the show cause procedure, recognising the importance of the swift progression of any claim where an asbestos disease has been diagnosed.

The Masters further demonstrated their commitment to the swift progress of these claims by confirming that, in the absence of compelling argument from any party for the need for cost budgeting, this is regarded as unnecessary in asbestos claims, given the potential for additional delay.

They emphasised the importance of the appointment of an expert mesothelioma and asbestos claims solicitor in these cases. Expert mesothelioma and asbestos claims solicitors understand the process and the procedure within the High Court for progressing asbestos disease claims. By instructing a solicitor specialising in mesothelioma and asbestos claims, mesothelioma victims are more likely to be spared unnecessary delay in receiving their compensation.

ASBESTOS-CONTAMINATED TALC

By Aliyah Akram, Barrister, 12 King's Bench Walk

In July 2018, a jury in St Louis, Missouri ordered that Johnson & Johnson, the multinational pharmaceutical company pay a total of $4.69 billion to 22 women who the jury found had suffered ovarian cancer as a result of using J&J's asbestos contaminated talcum powder.

In another case in New Jersey, decided in April of this year, a mesothelioma sufferer was awarded $117 million in damages when the jury found his use of asbestos contaminated Johnson & Johnson talcum powder had caused his cancer.

The size of the St Louis award, which included compensatory damages of $550 million and punitive damages of $4.14 billion, greatly exceeds the levels of awards ever made in cases in the United Kingdom. Equally the US legal system is very different from that in the UK, not least in terms of the law itself but also the resources that can be invested in class actions and even the fact that it is juries, not judges sitting on their own, who determine civil cases. The US cases do, however, show that talcum powder may be a widespread yet overlooked source of asbestos exposure, particularly for women.

Talc is the softest mineral in the world which when ground becomes the powder used in cosmetics and baby products. Deposits of talc are often found near to asbestos and so talc can become cross-contaminated with asbestos during the mining process. Although talcum powder manufacturers including Johnson & Johnson deny that their products have contained asbestos, numerous studies have suggested otherwise. One such study from as far back as 1976 tested 20 consumer talcum powders and found that ten were contaminated with tremolite or anthophyllite, both forms of asbestos.

In the St Louis case the plaintiff's attorney, Mark Lanier, argued that J&J had known that their 'Baby Powder' and 'Shower to Shower' products contained asbestos since at least the 1970s but had failed to disclose this to the FDA, the federal agency responsible for protecting public health in the US. J&J also failed to either withdraw the contaminated product or warn consumers of the dangers it posed.

Whether the contaminated talcum powder can cause ovarian cancer or mesothelioma is another highly controversial issue. In St Louis, the plaintiffs were able to provide the court with scientific evidence which they claimed proved that asbestos fibres enter the body when asbestos contaminated talcum powder is inhaled or applied.

They then pointed to the fact that asbestos fibres had been found in the ovarian tissue of many of the women to argue that the talcum powder must have been the cause of the plaintiffs' ovarian cancer. Similar arguments have been made in claims on behalf of mesothelioma sufferers.

Another 9,000 cases are currently being pursued in the US where it is alleged that asbestos contaminated talc has caused either ovarian cancer or mesothelioma. Unsurprisingly, given the scale of their potential liability, Johnson & Johnson have made clear that they plan to appeal this judgment and so it will be important to keep an eye on this developing area of litigation.

NEWS FROM THE NATIONAL CENTRE FOR MESOTHELIOMA RESEARCH

By Dr Maija Maskuniitty, Centre Manager

The National Centre for Mesothelioma Research (NCMR) at Imperial College London aims to lead discovery research into the underlying mechanisms of mesothelioma and lung cancer, identifying new diagnostics for patient stratification and new targets for mesothelioma therapy. Our projects range from genetic and genomic studies of mesothelioma, and deciphering the signals that drive the intense fibrosis that typifies mesothelioma, to looking at immunotherapy and using oncolytic viruses to treat the cancer.

We have now finalised our first genetic studies of mesothelioma, in collaboration with MesobanK, Professor Marion MacFarlane's group at the MRC Toxicology Unit and Professor Mark Lathrop's group at McGill University and Genome Quebec Innovation Centre. Following on from these studies, we are currently following leads to find genetic weaknesses in the mesothelioma tumours which could be exploited in new mesothelioma therapies.

Some of our latest research findings were presented at the British Thoracic Oncology Group (BTOG) Annual Conference in January 2018. Our postdoctoral research associates Dr Amit Mandal and Dr Anca Nastase presented their posters 'Copy number variations in malignant pleural mesothelioma reveal novel regions of genomic imbalances' and 'Targeted next-generation sequencing of malignant pleural mesothelioma identifies recurrent NRAS oncogene mutations', respectively. Dr Mandal won the first prize for his poster.

We will be presenting more of our recent research work at the ASHG (American Society of Human Genetics) Annual Meeting in San Diego this October. In addition, our Centre Director, Professor Bill Cookson will be at Mesothelioma UK's 13th Patient and Carer Day in Alrewas, Burton-on-Trent, on 19 October.

Aside from research, another major focus at NCMR is patient and public engagement. On Action Mesothelioma Day 2018, Professor Bill Cookson and Professor Sir Anthony Newman Taylor (Chair of the NCMR Scientific Advisory Board) were honoured to have been invited to talk at events in Kent and Liverpool, respectively.

www.imperial.ac.uk/ncmr

CLINICAL TRIALS

NEW NEMO CLINICAL TRIAL NOW OPEN

A new clinical trial has opened recently at several hospitals and has recruited four patients so far. The NEMO study investigates the activity of the drug Nintedanib in a double-blind, randomised phase II study.

Patients can be considered after completing four to six cycles of first line platinum-based chemotherapy for plueral mesothelioma and after confirmation of absence of progressive disease.

Recruiting sites are at:
- Weston Park Hospital, Sheffield
- Royal Marsden Hospital, Chelsea, London
- Royal Marsden Hospital, Sutton, Surrey
- South Tyneside District Hospital
- UHSM Wythenshawe Hospital
- Royal Marsden Hospital
- Kingston Hospital

These centres are in set-up and will open in due course:
- St James' University Hospital, Leeds
- Mount Vernon Hospital, Hertfordshire
- Maidstone Hospital
- Musgrove Park Hospital, Taunton

More details can be found in the Clinical Trials table with this magazine or at www.mesothelioma.uk.com/informationandsupport

MARS 2 CLINICAL TRIAL

An interview with Consultant Thoracic Surgeon, Mr Eric Lim

MARS 2 is a randomised control trial – what are the 2 arms of the trial comparing?
In MARS 2, we are evaluating chemotherapy alone or chemotherapy with surgery for mesothelioma. Participants in both arms will receive chemotherapy as standard of care in an expert mesothelioma treatment centre, and half of the participants will be allocated to surgery in between the 2nd and 3rd cycle of chemotherapy.

What are the key entry requirements for patients interested in entering the study?
The key entry requirement is that the disease needs to be confined to one side of the chest and deemed suitable for surgery. It is really important that patients are comfortable to accept either chemotherapy and surgery or chemotherapy alone.

How many surgical centres are now operating within the MARS 2 study and where are they?
There are six surgical sites in total and they are located in Leicester, Sheffield, Glasgow, Cardiff and London (Bart's and Guy's).

How many patients have been recruited to date?
As of 1 August 2018, 155 patients have participated in MARS 2.

When do you expect the study to complete?
We hope to complete recruitment into the study in two years (2020) and follow up participants for two more years, and for the results to be ready in 2023.

There are some concerns about patients with non-epithelioid disease being accepted into the study, what is your view on this?
Some overseas experts have stated surgery should not be considered in patients with non-epithelioid disease. Their opinion was not based on any reliable evidence (randomised trials). MARS 2 is the first study in the world to evaluate surgery for non-epithelioid disease in a clinical trial and if surgery proves beneficial (overall), then non-epithelioid patients may stand to benefit even more (as their prognosis in general is not as good). This in turn, will inform future expert opinion.

Can patients go into other chemotherapy /immunotherapy/targeted treatment trials if they are in the MARS 2 study?
Yes, we don't restrict any new treatments that become standard of care. Also, we don't restrict patients from participating in any other study once treatment (chemotherapy +/- surgery) is completed for MARS 2. We simply monitor and document the treatment that participants received. All we ask is they do not enrol in two studies (that are designed to improve survival) together at the same time as MARS 2, but rather after MARS 2 treatment is completed.

A feasibility study was completed prior to the trial expanding, when will results from the feasibility study be available?
There are no plans to analyse the results of the feasibility as it was not designed (powered) to detect any meaningful difference in outcomes - the trial will be analysed when fully completed to give everyone the best and most accurate results that we can deliver.

CLINICAL TRIALS

There has been a detailed patient experience study embedded within the MARS 2 study, what have the trial management group learnt from this?
The patient experience study reported many examples of positive experiences by participants, particularly relating to information and care received regarding chemotherapy and surgical treatment. However, with some missed opportunities where pro-active interventions could have significantly improved the patient experience such as reducing uncertainty, preventing unnecessary symptom distress and aiding understanding of the trial. Professor Angela Tod (who led the patient experience study) suggested a requirement to reflect on what patients want and need, at different points during and after the trial, in order to develop interventions to pro-actively assess, manage and meet patients, expectations and needs. We have been working on these suggestions, and developing deeper understanding with Dr Daisy Elliott and Dr Nicola Mills from the University of Bristol to continuously improve the experience of MARS 2 trial participants.

If you were a patient diagnosed with mesothelioma – what would you do?
If I was a patient diagnosed with mesothelioma, I would want standard of care (chemotherapy) and would consider surgery alongside this in a study setting (as I don't know if it works). The MARS 2 study offers these options. If there is evidence of disease progression, I would then seek further studies of new therapies. MARS 2 is designed to support and simplify this patient pathway in participants with mesothelioma.

Where can people find out more about the trial and initially explore their suitability for entering MARS 2?
So far, we have had patients enrolled from obtaining information in the following ways: visiting the CRUK website, contacting their local hospital oncology department, contacting the MARS 2 medical sites, writing to us at mars2-trial@bristol.ac.uk or writing to me personally e.lim@rbht.nhs.uk

This study was funded by the NIHR Health Technology Assessment programme (project number 15/188/31). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

UPDATE ON MESOTRAP

The MesoTRAP Trial has recently had an amendment approved by its funders (National Institute for Health Research and Health Research Authority) that will hopefully open up the trial to many more patients.
The following patients can now be included:

- Patients who have had a previous attempt at pleurodesis
- Patients with an Indwelling Pleural Catheter in place for any length of time (removing the 28 day time limit)

MesoTRAP now also includes an Observational Sub-Study, which will run in parallel to the main randomised study. The Observational Sub-Study will collect observational data on patients with malignant pleural mesothelioma and trapped lung who otherwise do not meet the entry criteria for the main study. This group of patients is currently not well studied so the aim of the sub-study is to provide data to inform patient care and identify possible avenues for research.

WELCOME TO FUNDRAISING

NORWICH 10K

A team from Anglia Asbestos Disease Support Group (AASG) ran the Norwich 10k in memory of John Jackson. The team were supported by ASSG's sponsor, Ashton's Legal and Ashton's Charitable Trust. Together, they hope to raise enough funds for a dedicated Mesothelioma UK nurse specialist for Norfolk and/or Suffolk.

£1,000 FROM LUNCH4LIFE

Mesothelioma UK Clinical Nurse Specialist Karen Lord was presented with a cheque for **£1,000** recently from the charity Lunch4Life.

Zara and Lorna Ponti, chairman of Lunch4Life, presenting Karen Lord with a cheque.

Zara's husband, Bruce, died of mesothelioma in Leicester in 2016. He and Zara ran a demolition company in Windsor and were sponsors of the charity Lunch4Life. Lunch4Life raises considerable sums of money to provide breast cancer equipment for the local hospital following its founder, Lorna Ponti's diagnosis. More recently, prostate cancer care has also benefitted.

Zara is on the board of Lunch4Life and arranged for **£1,000** to be donated to Mesothelioma UK. The money was part of a larger sum raised through the charity's annual fundraising ball.

GUNG HO!

Myself and two friends, Adam Balawajder and Martin Clark took part in the Leeds Gung Ho assault course in April and decided to raise money for Mesothelioma UK as my dad was unfortunately diagnosed with this cancer in April 2017.

We quickly smashed our original target of £200 and our revised target of £500, raising **£600**.

John Doran

HOTTEST MARATHON ON RECORD!

I ran this marathon in memory of my wonderful Dad, Bill Tucker who lost his battle with mesothelioma in November 2009.

After months of training in the freezing cold, snow, ice, wind and rain, it was a bit of a shock for marathon day to be 24 degree Celsius, but when the going got tough, I remembered why I was doing it and thoughts of my Dad cheering me on got me through!

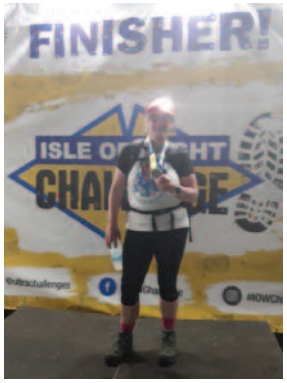
I had the best support that I could have wished for from my Mum, husband, children and all of my friends who have supported and sponsored me so generously! I'm so pleased to raise this for Mesothelioma UK.

Michelle Roose

SPARTAN 6K

Lee Bernard competed at the Spartan 6km sprint race in Sevenoaks Kent and raised **£800**. He competed again at the end of June in the Spartan Super which was 12km plus and the Spartan Beast in October which is 24km plus. His aim is to complete all three in a calendar year and earn the Spartan trifector medal.

ULTRACHALLENGE



In May, I took on the Isle of Wight Ultra challenge – walking 106km around the whole Isle of Wight coastal path in two days. Despite my training, nothing prepared my feet for the extremely hot weather that weekend. It got to the point where I daren't take my walking boots off, for fear that they wouldn't go back on again as they had swollen so much.

There were times when my feet were so painful, I didn't know whether I would finish the 106km. But I thought of my mum, who died of pleural mesothelioma in September 2016, and also of my dad, who had wanted to walk the island coastal path with me, but died aged 53 in 1997. These memories and the support of my friends and family kept me going. It seemed that every time I doubted myself finishing, a lovely message would pop up on my phone to give me the boost I needed.

My parents were both keen walkers and belonged to a rambling group. They would have both loved the walk...but I believe they would have stopped and admired the scenery more, tasted the local delicacies and supped some cold beers on the way round! Not walk continuously for 30 hours! They would be very proud of me, but I could hear my mum all the way round telling me that I was over-doing it!

I hope the money I have raised will help the families and sufferers of mesothelioma to get support and advice during their terrible journeys with this awful disease.

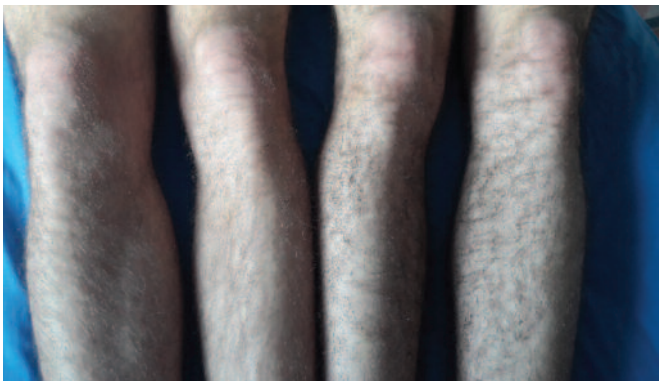
Dianne Lawrence

PAUL SCARROW

Paul Scarrow died from mesothelioma earlier this year and was cared for at the Royal Papworth Hospital by our Clinical Nurse Specialist, Kate Slaven. Paul's wife and friends arranged a charity football match in June which raised an amazing **£7,076** for Mesothelioma UK.

LEG WAX!

Brave twins, Matthew and James, decided to raise money for us by letting their friends wax their legs! The boys' grandma died of mesothelioma and they wanted to do something in her memory to raise money and awareness. Their friends had a great time waxing them and the boys raised **£955**.



IRWIN MITCHELL'S DRAGON BOAT RACE

On 24 June 2018, members of the asbestos teams from the Leeds and Sheffield offices of Irwin Mitchell Solicitors took part in the Bradford Dragonboat Festival at Roberts Park, Saltaire, to raise funds for Mesothelioma UK.

Thanks to amazing support from friends and colleagues, the team managed to raise **£1,666.25** (including gift aid). In addition, the Irwin Mitchell Charitable Foundation has generously agreed to top up the donations received by **£453.00**, giving a grand total raised of **£2,119.25**.

The team from Irwin Mitchell consisted of Oliver Collett, Ian Toft, Lucy Andrews, Hannah Robinson, Alex Foster, Dominic Riley, Leanna Bolton, Adrian Budgen, Simone Hardy, David Johnston-Keay, Kerry Ford, Leah Hutchinson, Nicola Handley and Mark Handley. Last, but most certainly not least, the team were very ably assisted by Mesothelioma UK Clinical Nurse Specialist, Helena Stanley.

We could not have wished for a better day splashing around on the river. Despite our absolute novice status as Dragonboat paddlers, we are delighted to say that we did not come last (27th out of 39 – not a disaster) and we managed to shave off 10 seconds from our first race to our last.

The team have acted for mesothelioma victims for many years and have seen at first hand the devastating effect that this awful disease can have on individuals, friends and family. It was great to be able to do something to help raise money and awareness for the fantastic support services provided by Mesothelioma UK.

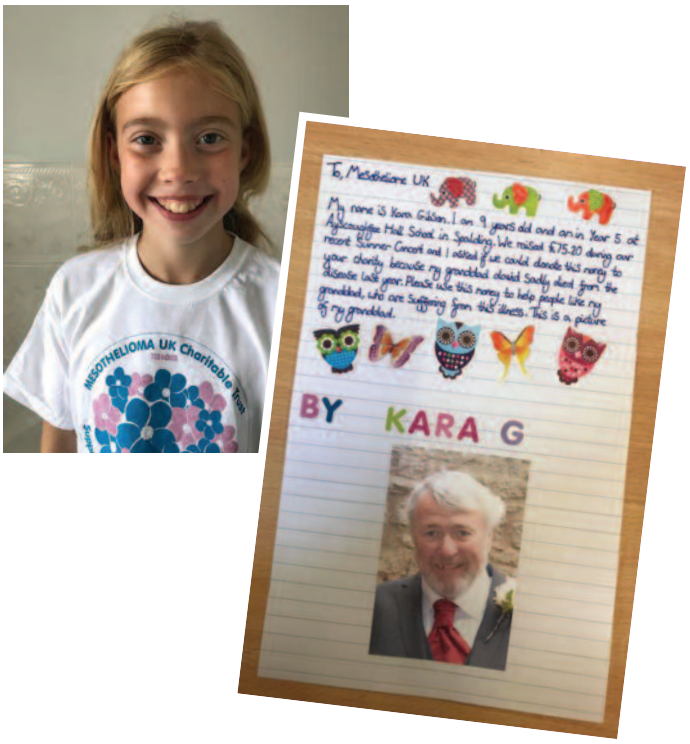
MUFFINS FOR MESO

Beecham Peacock Solicitors held a Muffins for Meso event because we act for a large number of people with asbestos related conditions in the North of England, and helping the charities that support those people with asbestos illnesses is something we feel strongly about. We have also supported through our links with our local charity, Mick Knighton Mesothelioma. We had a selection of cakes and both the staff and any clients that came into reception were encouraged to take a cake / muffin or biscuit and donate what they could afford.

Vicki Wanless

KARA'S FUNDRAISER

9 year old Kara donated the **£72.50** raised at her summer concert to Mesothelioma UK in memory of her grandad. She wrote to us and asked us to "please use this money to help people like my grandad, who are suffering from this illness".



JANICE TO REPRESENT GB

I completed the Chrono cycle time trial in my age group at the Tour of Cambridgeshire, raising **£2,365**. The amazing news is that I qualified to represent GB in my age group at the UCI World Championships at Varese, Lombardy, Northern Italy at the end of August.

Janice Houghtonwallace

MORE MUFFINS FOR MESO

Irwin Mitchell have had strong links with Meso UK, working together since the charity launched in 2004 to help get those who have been diagnosed the justice they deserve. Having witnessed first hand the devastating effect mesothelioma has on the lives of our clients and their families, the Workplace Illness Teams across the country jumped at the chance to raise money for such a great cause.

Our budding bakers in Birmingham got creative with muffin recipes. The treats were a hit and raised **£105**. The Bristol Office made baskets of tasty treats to raise **£102**. Our Cambridge team made raspberry, rocky road and lemon drizzle muffins. The team raised **£91.10** and continue to hold a weekly bake. Our London team raised **£20**, and the Sheffield office raised **£96.85** with their tasty bakes.

Across the Irwin Mitchell offices, we raised a whopping **£414.95** for Mesothelioma UK. The event was a great chance to get together and raise awareness for the condition and the charity, whilst keeping the offices well-fed in the process!

Erika Wright, Irwin Mitchell LLP, Birmingham

SWIMATHON

Congratulations and thanks to Kira and family (Charlie - age 4 and Grandpa, Spike - age 77) on braving the weather and completing their mile-long swimathon, raising **£180**.

PUPILS AND STAFF WALK FOR MESO

Pupils from Altrincham College Secondary School in Timperley, Cheshire took part in a charity walk on Wednesday 28 March. All staff and pupils took part in the 10 mile walk, which was a huge success (despite the blisters and aching feet!). They made a donation of **£1,000** in support of Mesothelioma UK.

LEIGH DAY SOLICITORS

A team at Leigh Day Solicitors in Manchester held a Muffins for Meso bake off on Thursday 24 May.
We had seven contestants who all baked a variety of lovely cakes and our blind tasters, including our Mesothelioma specialist lawyer Kevin Johnson, scored the muffins. The clear winner was our asbestos team secretary, Sarah Lord, with her carrot cake muffins. The muffins were then sold and we raised **£71.72**.

Steven Dickens, Leigh Day, Manchester

ISLE OF WIGHT CHALLENGE

The challenge was held on 5-6 May. We began in Chale on the south of the island and we walked clockwise around the island, finishing in Chale. We had aimed to complete the 106km route in under 30 hours, walking through the day and night with only short breaks, and we achieved an amazing 26 hours! Beating our previous 27.5 hours record in the Trailwalker Challenge back in 2015 which was just fantastic! We raised **£3,317.44**.

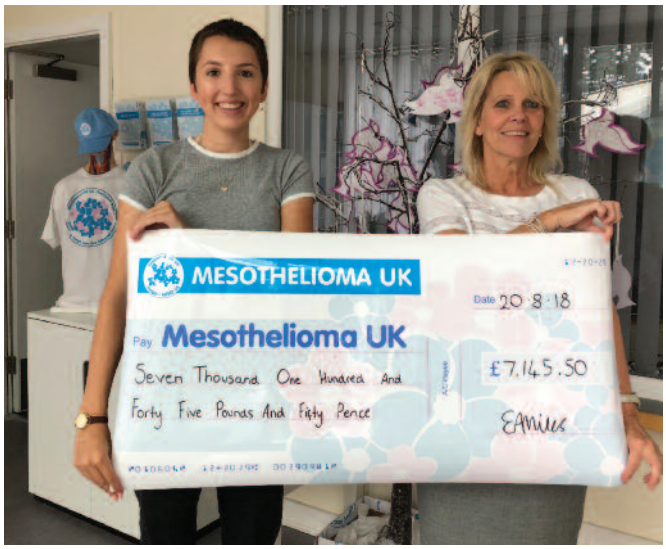
Gavin, Andy, Ruth, Magda, Jon, Ben and Kamila

WILLIAM PRINN

This will be my 6th year of running the Greater Manchester 10K and the 5th time running for Meso. My Granddad suffered with this relatively new and extremely rare cancer, Mesothelioma is currently very under researched and extremely unknown so a donation would be hugely appreciated to enable more research to be done into this horrible disease.

William raised **£187.50**.

LIZZIE BRAVES THE SHAVE



I shaved my hair off as I wanted to raise awareness of this amazing charity and make my grandad proud. I felt doing something like this will make me stand out from the crowd and make as much money as possible! In the end I raised a total of **£7,145.50** which is so much more than I expected but I am so pleased with myself for doing this incredible deed. This experience was truly thrilling and will probably be one of the best things I will ever do in my whole life!

Lizzie Miles

14 year old Lizzie also organised a quiz night and collected donations outside her local supermarket to raise money. In addition she invited Mesothelioma UK Head of Services to speak at an assembly at her school to raise awareness.

CLIMBING SNOWDON FOR ANDY

Andy's 53rd birthday was on 20 April – one of the first very hot and beautiful days of this summer that he would have loved. At that point we were still hopeful that, although he was very unwell and the two trials that he had undertaken at Leicester had not been successful, he would be able to embark on some further treatment. I decided that this birthday had to be a special one, ordered an extra comfortable deckchair for him and invited a bunch of his local friends for gin and tonics on the patio. A beautiful evening ...so glad we did it. We even managed a night away the following night in a gorgeous b&b in deepest Surrey.

But very, very sadly, things changed dramatically in the next few days and I lost my lovely husband, and Zak and Mia, their dad on 12 May, just three weeks after that lovely evening.

I was lost and devastated but needed a focus. I knew I wanted to raise money for Mesothelioma UK and wanted it to be by doing something challenging but achievable that the three of us could do together. In 2014 we had planned a trip to Snowdon but after Andy's diagnosis had had to put it on hold. Now I felt was the time that we could honour Andy's memory by doing the climb. And on 5 July that's what we did.

Of course, at the time of planning I was thinking about kagoules and waterproof trousers. By the time we did our walk the heatwave was upon us and I knew this was going to be challenging in a different way. And it was... Somehow, we were convinced by the taxi driver who picked us up from Bangor station that it would be far more interesting (and really just as easy - or did he mean just as difficult) to climb the Pyg route and descend the Llanberis route. That afternoon I went into every outdoor shop in Llanberis to canvas opinion. Respect the mountain they all said - and yes, we would be fine as long as we took lots of water and wore lots of sun cream.

So, we got the 9am bus to the Pyg route start with Mia telling me - just relax and enjoy it mum - and started climbing at 9.30. It was hard - so hard. Clambering was involved and lots of pep talks from Zak about having a positive mental attitude. That mountain was so damn high! But the encouragement and solidarity of passers-by and people we were keeping pace with was amazing. And the humour ... In the group behind me I heard a man tell his wife "if you wanted a walk in the park Sandra, you should have gone for a walk in the park". After two hours of hard climbing the summit looked very far away and the next 40 minutes were the toughest.

Twenty minutes later finally, finally we reached the last few steps ... and as we did a choir who had just before arrived at the summit by the little train began to sing Hallelujah. I promise I didn't imagine this. In a film script it would have been rejected as a cliché. It was so wonderful, so moving and so amazing. And then followed the euphoria buoyed near-jog down the mountain. I nearly tripped a thousand times, but Andy's spirit righted me, and I never quite lost my balance. I can't quite believe that he wasn't there in person to share it - he would have loved it.

We were overwhelmed by the financial and moral support of our family and friends and also by my wonderful employer Event Communications and my colleagues there. So many words of advice and encouragement beforehand and congratulations afterwards. It has got us through to where we are now. The road ahead is uncertain, and we miss Andy more every day but knowing we achieved this thing together and raised as much as we did makes us so proud.

And a word about what Mesothelioma UK meant to us... from the moment we went to Leicester and met the wonderful nurses there we felt loved and supported. Jo, Karen and Sarah ... I have to mention you by name as Andy loved you all. You scooped us up (literally in Jo's case) and gave us words of advice and compassion on even the darkest days. Without you this unbearable journey would have been impossible and I thank you all.

And just a p.s. we had an email a couple of days ago from Just Giving saying that we had been in the top 1% of fundraisers in July. Couldn't be prouder.

Gill, Zak and Mia raised a fabulous **£8,522.50** including Gift Aid.

ARCA CHARITY WEEK 2018

This year the ARCA Charity Week was from 10–14 September and both ARCA staff and some of the Association's members raised funds for Mesothelioma UK.

ARCA staff completed a 5k Colour Obstacle Rush, held at Uttoxeter Race Course in July. After running, jogging and walking the 5k in the hot sun, the team reached the finish line covered in lots of coloured paint and having tackled 20 obstacles!

They have also held a games night, with teams playing five different games, and held a bake sale. ARCA staff and members also took part in activities on and around the Charity Week; bike challenge, muddy obstacle runs, zip wire challenges and bake sales.

Thank you to everyone who took part!

NORWICH 50-MILE CYCLE RIDE

Rosemary Giles, Partner – Irwin Mitchell LLP (Cambridge) and Angela Longe, a Thoracic Surgical Nurse successfully completed the Norwich 50 mile Cycle Ride on Sunday 3 June 2018 raising funds for Mesothelioma UK on the way.

The route took them from the centre of Norwich out to Walcott on the North Norfolk Coast and back into Norwich.

Rosemary and Angela completed the course in four hours and raised **£1,117.50** for Mesothelioma UK.

Both said afterwards, that despite the obvious weariness, they really enjoyed the ride, helped of course by the knowledge that they had raised so much money for such a worthwhile cause.

LIAM'S CYCLE CHALLENGE

Some of you may have read Liam's story on our website or watched his video. He is a 31 year old who was diagnosed with mesothelioma last year.

Fortunately, Liam is currently symptom free and not in any pain and is determined to 'crack on with life.'

Liam is also passionate about raising awareness of mesothelioma and funds for clinical trials and research. To do this, he has set himself a few challenges. The first is a bike ride from Gretna Green in Scotland, to Burton-on-Trent, to arrive at Mesothelioma UK's Patient and Carer Day.

Liam is funding the ride himself and it will be a 'warm up' for his main challenge which is to cycle from Nottinghamshire to Alicante in Spain next year.

Liam says: "Whilst I am still able, it would be my dream to be able to give something back to the people who supported my family through our darkest hours."

The Alicante bike ride will involve travelling across five countries - England, Holland, Belgium, France and finally, Spain and Liam hopes to complete it in 14 days.

Liam would be very grateful for any support e.g. help with fuel and travel costs (ferry, hire of support vehicle), help with accommodation costs or a donation via the JustGiving page www.justgiving/com/liam-bradley14.

You can read Liam's story and watch his video on our website at www.mesothelioma.uk.com/patientstories/liam-bradley/

Good luck Liam!

IN MEMORY OF KEVIN FRANKTON

I am extremely proud to have been part of a couple of charity events this year in memory of my late father, Kevin Frankton who passed away in December 2017 from mesothelioma. My family and friends have been amazing over the past six months who have organised, taken part in and supported this wonderful effort of raising funds and awareness.

Kev Smith, a friend of my father's, organised a Charity Golf Day on Sunday 8 April at Nottinghamshire Golf and Country Club. It was a fabulous day, 44 people took part and they raised a fantastic **£365**.

Jo and Darren Cooper, wonderful friends of my father, organised a Charity Gig and after just a few short weeks of planning, held it on Sunday 9 May. The landlords, Andrew and Maggie at The Old Volunteer pub, along with a local band, Sing When Your Blue, local singer Evie Marlow and with a BBQ, raffle and auction, all items donated by friends and local people and businesses made it a fantastic success. Over 200 people attended and had an amazing time. Darren Cooper works for Howdens and in support, donated £500 and we managed to raise **£2,432.62**, and so our overall total in memory of my father is £**3,297.62**.

I personally cannot thank the charity enough for the work they do and I hope that one day, through the money I have raised, I can make a difference to someone else's life.

Hannah Frankton

BRIAN WALLIS

I am sure that you will be pleased to learn that AADSG - Norfolk members and volunteers have so far raised over **£6,730** towards the Norfolk MNS fund. The fund was launched in January 2018 and is being administered by Ashtons Charitable Trust, who collect donations and manage the My Donate page on behalf of AADSG. The fund is intended to assist with the placement of a Meso Specialist Nurse in the Norfolk/Suffolk area in due course.

Brian Wallis

SUSAN FARRELL

Susan is a keen amateur painter and contributed a number of her paintings to the sale.

"My event was a yard sale during the Fiddler's Green International Music Festival in Rostrevor Co Down. It was a joint fundraiser with money also going to the lymphoma charity. Here's me at the yard sale painting en plein air! I sold some of my paintings towards funds for Mesothelioma UK, a UK charity supporting those affected by cancers caused by asbestos exposure. Pete, also in the picture, and I got the most wonderful support from the kind and generous people of Rostrevor who endlessly put their hands in their pockets for charity. Many people from Rostrevor will remember Richard Lewis, my husband, who unfortunately died because of asbestosis exposure and this event has definitely helped raise awareness of this disease.

"In total those generous people of Rostrevor helped me raise **£171**, so thank you to all who supported us."

If you, a colleague, friend or family member would like to be added or removed from the mailing list to receive a printed or online version of the quarterly Mesothelioma Matters magazine, please email info@mesothelioma.uk.com

The Mesothelioma UK Charitable Trust exists to raise funds to support the services provided by Mesothelioma UK and any sponsorship, grants or donations made to the charity support this.

Mesothelioma UK would like to thank all of our wonderful donors.

If you would like to find out more about becoming a Corporate Partner or Friend, contact our Fundraising Manager, Jill Lemon on 0800 169 2409.

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