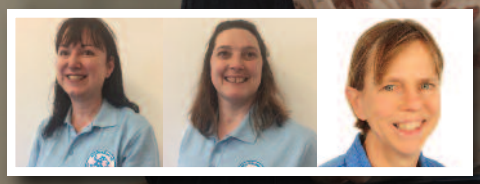
MESOTHELIOMA MATTERS

Winter 2018

MORE patient feedback needed to improve service



Introducing new adopted nurses

Patient and Carer Day 2018

Sarah makes an impact in Wales

MESOTHELIOMA UK
Supporting People With This Asbestos Cancer

MORE PATIENT FEEDBACK NEEDED TO IMPROVE SERVICES

Mesothelioma UK is inviting patients to give feedback on what their experience of investigations, treatment and care has really been like.

The MORE survey (Mesothelioma Outcomes, Research and Experience) will 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 which kind of support services we should be offering.

The survey consists of three sections – patient experience of care, quality of life and clinical information. It is completely confidential and will be anonymised.

We're looking for 600 patients to complete the survey in the next six months. Patients will be invited to take part by their nurse or support group, or patients can call our freephone helpline on 0800 169 2409 or email us at info@mesothelioma.uk.com to request the survey.

Based on the feedback that we receive, we will produce recommendations and circulate them to the wider mesothelioma community and healthcare providers.

Please speak to your nurse or get in touch with us if you would like to help us to improve the support available to patients.

NEW DOCUMENTARY FILM LEAVES AUDIENCE BREATHLESS

Colleagues from Mesothelioma UK recently attended the UK premiere of an award-winning documentary called 'Breathless' on the impact of asbestos in the developing world countries.

Breathless, which had its global premiere at the International Film Festival in Brussels this year, aims to show how asbestos companies cynically expanded to the less-developed world to perpetuate a dangerous industry for profit.

In India, the asbestos industry continues to expand which will cause asbestos-related deaths for decades to come, according to the filmmakers.

The documentary from the Storyhouse production company, tells of Eric Jonckheere, whose mother, father and two brothers died from mesothelioma, who travels to the largest asbestos dump in India to find a community affected by the same Belgian company. It is a story of profit over people, but also of how ordinary people can stand up to corporations.

Krishnendu Mukherjer, a dual qualified barrister from Doughty Street Chambers, travels to India with Eric and also explains how the asbestos industry spied on him and other campaigners who campaign against the asbestos industry and spread knowledge regarding the dangers of asbestos to life.

You can find out more about the film on its Facebook page at www.facebook.com/movie.breathless/

INTRODUCING OUR NEW ADOPTED NURSES

After we invited NHS Trusts across the UK to have their lung cancer nurses 'adopted' by Mesothelioma UK, we're delighted to announce the first recruits that will strengthen our Clinical Nurse Specialist team and help us to extend our support and care for mesothelioma patients.

The main aims of the adopted nurse posts are to:

- Support the development of existing nurse specialists
- Enhance specialist mesothelioma knowledge base and skills
- Enhance the outcomes and experience of mesothelioma patients and their families

Jenn Latham

Jenn is based at Raigmore Hospital in Inverness, a medium-sized hospital covering the whole of the north of Scotland. Having qualified in 1993, she's been an Advanced Lung Cancer Nurse, specialising in early detection, respiratory medicine and pleural effusions.

Throughout her career, Jenn previously worked as a staff nurse in acute medicine, ITU, ED and was a ward-based nurse practitioner, mainly in respiratory, for six years. Jenn has focused on pleural diseases and pleural metastases including lung, breast and bowel cancers.

She is also a national representative on the British Thoracic Society Pleural Sub Advisory Group.

Lucy Heycock

Lucy will work alongside her colleague, Jenn, in Inverness. She has spent the last five years as a Lung Cancer Nurse having previously worked as an Oncology Nurse in Oban where her focus was general oncology, palliative care and chemotherapy, but included lung cancer and mesothelioma. She is a committee member for the National Lung Cancer Forum as well as the Scottish Lung Cancer Nurses Forum Committee.

The geographic range of patients is from the Western Isles down to Inverness. In her new role, Lucy is looking forward to taking the opportunity to having input into, and support from the wider Mesothelioma UK team, and linking into national organisations for guidelines, best practice and networking.

Joanne Darby

Joanne is a Lung Cancer Nurse for the University Hospitals of Morecambe Bay NHS Foundation Trust, covering the areas of Lancaster and Barrow. She was previously a Chemotherapy Nurse for two years and prior to that, was an Acute Medical Nurse, with both positions based at Morecambe Bay.

Joanne is looking forward to working with the Mesothelioma UK team, utilising their education and expertise, exploring clinical trials and surgical options for patients, and organising support groups for the local area.

Karen Price

Karen is a Lung Cancer Nurse Specialist, working alongside Joanne and also employed by the University Hospitals of Morecambe Bay NHS Foundation Trust.

She was previously an Acute Respiratory Ward Manager and Ward Sister at the Royal Lancaster Infirmary. She has significant experience in dealing with patients with respiratory conditions and the high incidence of mesothelioma in nearby Barrow has led to her interest in the treatment of mesothelioma.

Karen is involved with the new CLASAG support group, to be launched in January 2019 and featured on page 17 of this magazine. Both Karen and Joanne will be integral to the development of CLASAG.

Helen Higham

Also joining our Mesothelioma UK Clinical Nurse Specialist team is Helen Higham, based at Wythenshawe Hospital, part of the Manchester University Foundation Trust.

Helen's is a part-time role, working alongside Mairead Dixon. She is funded by Mesothelioma UK in an adopted nurse role. She will focus on treatment and care for existing and new mesothelioma patients, and will also get involved with local support groups.

Helen was previously Senior Cancer Awareness Nurse with Cancer Research UK, prior to which she worked with the Acute Oncology Management Team at The Christie Hospital. She has significant experience in Specialist Palliative Care and was a Macmillan Clinical Nurse Specialist in the community for ten years.

Nurses can be contacted via the helpline on 0800 169 2409.

HASAG SUPPORT FOR CLINICAL NURSE SPECIALISTS

The HASAG asbestos disease support group in Hampshire has been a long-term supporter of Mesothelioma UK and continues its invaluable contribution by offering to fund our Southampton Clinical Nurse Specialist as a full-time role. Currently, Helen Wilkes, who also focuses on Armed Forces patients, works part-time and HASAG's generous offer will enable this role to be increased to full-time.

The funds to cover the extension of this post were raised from HASAG's activities for this year's Action Mesothelioma Day.

Lynne Squibb and her sister, Diane, started HASAG in 2006 after their father, Dave sadly passed away after contracting mesothelioma. Lynne says: "We've previously helped with funding for Anne Moylan's CNS role in Portsmouth and our Trustees were so delighted with the value that Anne has brought to her role that they wanted to replicate this arrangement in another setting. Covering Helen's role is the perfect solution for us and we're confident that she will continue to make a real difference to mesothelioma patients and their families."

HASAG covers the South of England, South East, London and the Home Counties. The majority of HASAG's work is supporting patients at home to receive government payments, compensation and ongoing support. HASAG recently announced that in the first six months of 2018, they supported 327 patients and carers to make claims for benefits and state compensation, helping them to access over £5.5 million in lump sum payments and benefits.

HASAG
ASBESTOS DISEASE SUPPORT

NATIONAL LUNG CANCER FORUM FOR NURSES ANNUAL CONFERENCE

Meso UK Clinical Nurse Specialist and Team Leader, Anne Moylan, reports on this year's National Lung Cancer Forum for Nurses (NLCFN) annual conference

The NLCFN annual conference is always an excellent opportunity for nurses in the field of thoracic malignancies to meet, share good practice and take a few days out of practice to immerse themselves in an educational programme specifically for them.

This year, the conference took place at the International Centre in Telford, a purpose built convention centre on the edge of Telford town centre. I thought it was an excellent venue with plenty of room in the exhibition area and the lecture theatre, with hotels to suit various budgets on the doorstep.

The theme this year was 'Building Hope in Challenging Times' and the scene was set in the first session with presentations on awareness and attitudes to lung cancer, the implications and experience of implementing the optimal lung pathway, and feedback from the NLCFN annual workshop.

In the afternoon there was a heated debate - 'This house believes that DS1500 should not be used for every patient with stage IV lung cancer'. Natalie Doyle (for) and Rachel Thomas (against) both presented strong arguments to support their stance but at the end the consensus remained that it was appropriate to complete in this circumstance and I suspect this is a subject that is likely to be raised again as new treatments impact on survival.

The second day began with the AGM of the NLCFN followed by an update on mesothelioma and Mesothelioma UK. Presentations on audits, research, an update on Mesothelioma UK activity and the Supporting Our Armed Forces Project were followed by an incredibly moving talk from a mesothelioma patient, David Staley, and his wife, Alison.

Diagnosed aged 39, David spoke about the impact on him and his family, and his hopes for the future, and received a well-deserved standing ovation. Everyone in the room was clearly moved by his story and it really served as a reminder of why we do this job and the impact that nurse specialists can have on patients.

After lunch there was an inspiring session of talks from nurse specialists who are influencing the patient journey in their areas. This conference is always a fantastic opportunity for nurses to showcase the excellent work that is being done around the country and it was inspiring to see the impact that we can have.

Ann Burgoyne delivered an inspiring presentation about how we should care for our own emotional wellbeing as well as the patients for whom we care. Amongst other strategies, she guided the audience through a '3 minute pause' and gave lots of food for thought for self-care.

Anne Moylan

Drew Povey closed the conference with another inspirational motivational address. Once again, he engaged the audience on topics of self-worth and hope. His leadership advice was so valuable and relevant.

The conference ended on a very positive note with affirming and motivational sessions reminding us to take care of ourselves in the high pressure environment in which we work every day. Next year marks the 20th anniversary of the Forum with the conference being held from 14-15 November at the Radisson Blu Edwardian Heathrow, London – save the date!

MESOTHELIOMA UK RACE NIGHT 2018

Under the theme 'Celebrating Mesothelioma UK', we held our first ever gala fundraising event: A Night at the Races. Held on the night before our Patient & Carer Day at the National Memorial Arboretum (NMA) in Staffordshire, conditions were favourable for almost 100 racegoers dressed in their finest attire for an evening celebrating our achievements over the last nine years as an official standalone charity.

The first two races, run in between delicious starters and main courses provided by the NMA, showed that owners could be in the money but to be in the running for serious winnings, you had to back the right horse. With half the take from every race going to the charity and the other half split between those who bet on the winning horse, the odds were good that Mesothelioma UK was going to be a winner!

We paused the racing briefly to honour the winners of the first ever Mesothelioma UK Awards and continued the racing well into the night.

As we reached the home stretch, everyone agreed that it was a delightful way to celebrate Mesothelioma UK's achievements while raising funds to keep the charity as the front runner in supporting patients and carers with mesothelioma, as well as research into the disease.

Image above © Martin Lansley

MESOTHELIOMA UK PATIENT & CARER DAY 2018

We held our annual Patient and Carer Day on a crisp, sunny Friday in October at the National Memorial Arboretum in Staffordshire. For those that don't know, the NMA is a 150 acre centre of remembrance to honour those who have served, and continue to serve our nation in many different ways. There are more than 300 memorials dedicated to armed forces, emergency services and others that acknowledge their personal sacrifice to this country and our 170 attendees started the day with an introduction to this unique venue from David Bardell, a volunteer at the NMA.

Chair of Trustees, Professor Mick Peake, then introduced Dr Paul Beckett, Consultant Respiratory Physician at the Royal Derby Hospital, who presented insights from the National Mesothelioma Audit. Professor Dean Fennell, Consultant Thoracic Medical Oncologist at University Hospitals Leicester, then spoke about 'stratified therapy for mesothelioma'. Among his many insights was a comment that immunotherapy has promise but requires personalisation. He also gave information on starving mesothelioma by arginine deprivation, which is now in a clinical trial (ATOMIC).

Continuing the research theme, Professor Bill Cookson, Professor of Genomic Medicine at Imperial College London, then spoke about the complexity of analysis in the lab. We wrapped up the first part of the day with a very interesting panel discussion during which the audience certainly challenged the experts.

After a brief break, Ian Jarrold, Head of Research at the British Lung Foundation, spoke about research that Mesothelioma UK has funded including the RADIO Meso project, which was presented by Professor Angela Todd and Dr Beth Taylor, both from Sheffield University. We distributed hundreds of postcards with the 10 top tips for communicating a diagnosis of mesothelioma, which you can download as a PDF from our website by searching for RADIO Meso.

Mesothelioma UK's Fundraising Manager, Jill Lemon, then gave an update on the variety of fundraising activities that our dedicated supporters are performing and the various ways in which we are supported by amazing sponsors, donors and volunteers. She was followed by an inspirational patient story from Tim Stokes called 'Dad Years and Adventure Selfies', discussing his diagnosis and treatment experiences as well as his escapades on and off an electric bicycle.

Professor Mick Peake then presented Tim with our first 'Most Inspirational Fundraiser of the Year Award', a well-deserved thank you from all who have benefited from his efforts.

After lunch, Institution of Occupational Safety and Health (IOSH) Vice President, Michelle Muxworthy, introduced the IOSH No Time To Lose campaign, which is raising awareness of work-related cancer and helping businesses to take action.

Jason Addy, archivist at the Spodden Valley Trust, then gave a powerful presentation on the history of the asbestos trade in the UK, giving an insight into the meticulous research on one of the world's largest asbestos textile factories, the Turner & Newall site in Rochdale, Greater Manchester.

A buzz could then be felt around the room as people heard that the legendary Liam Bradley had arrived, having cycled over 200 miles from Gretna Green that morning. Liam was diagnosed in 2017 at the age of just 30 years old and is refusing to allow mesothelioma to stop him 'cracking on with life'. He entered the room, supported by his wife and young daughter, to a standing ovation and a wave of released emotion from the attendees. Still out of breath from the cycle ride, which is just a warm up to his planned fundraising ride to Alicante in 2019, Liam said: "I refuse to be a statistic." You can read more of Liam's story in the Patient & Family Experiences section of our website.

Jo Hargrave, Thoracic Surgery and Mesothelioma Nurse Specialist at St. Bart's Hospital London, then talked about the decision to have surgery or not, followed by Victoria Adinkra, Macmillan Breast Care Nurse from East Cheshire NHS Trust, who gave a realistic insight into fatigue and how to manage it.

The final presentation of the day was from Mesothelioma UK Clinical Nurse Specialist Team Leader, Anne Moylan, who introduced our Armed Forces project, particularly fitting considering the venue of this year's event.

We then opened the floor to any questions or comments from attendees, which led to some interesting insights with healthcare professionals, researchers, patients and carers all contributing to the discussion.

Attendees were then invited to a trolley bus tour of the National Memorial Arboretum before saying au revoir, 'until next time', rather than goodbye.

Ian Jarrold, British Lung Foundation

Liam Bradley and Liz Darlison

MESOTHELIOMA UK AWARDS 2018

We are proud to announce the winners of our first ever awards, which celebrate the amazing work of our supporters. We presented the awards at our recent Race Night and Patient & Carer Day and would like to thank all of you who support us. The winners of the 2018 Mesothelioma UK Awards were:

Charity Partner of the Year
Mick Knighton Mesothelioma Research Fund
Chris Knighton is the driving force behind the research fund, has been Mesothelioma UK's longest serving charity partner and donated the largest amount in 2017/18 in support of our charity.

Corporate Donor of the Year
Royds Withy King
Being one of our Gold Corporate Donors since 2013, Royds Withy King has been consistently supportive over the years, always first to step up in funding and supporting any Mesothelioma UK initiatives. The company has been the largest corporate donor across all events.

Most Inspirational Fundraiser of the Year
Tim Stokes
Tim has always been a bike rider, he races cycles and loves it. It is his passion. He has mesothelioma, but that has not stopped him! Tim told his story at our Patient and Carer Day so this award is to recognise how inspirational he is.

Special Contribution of the Year
Brian Wallis
Having lost his dear wife Rosemary to mesothelioma, both having had long service with the RAF, Brian has worked tirelessly to help others. He became an ambassador for Mesothelioma UK several years ago and has since travelled far and wide attending fundraisers on our behalf. Brian has now helped to open three support groups in the Anglian region and is also an active member of the working group for Mesothelioma UK's Armed Forces initiative.

Corporate Partner of the Year
Asbestos Removal Contractors Association (ARCA)
ARCA members hold a charity week each year supporting their chosen charity where many members get involved, taking part in various events including biking, abseiling, skydiving, walking and baking cakes. Last year, Mesothelioma UK was their chosen charity and the

Brian Wallis (L) and Mick Peake (R)

members raised an amazing amount of both awareness and funds in support of the work we do. They also linked their members' asbestos training days with each of our mesothelioma nurse specialists in their area which was of great benefit to all.

Private Donor of the Year
Mr and Mrs Miles

Junior Fundraiser of the Year
Poppy Lake
Poppy is nine years old and loves singing, especially to her dear grandad Michael Arthur Cross. Sadly, Michael died and in his memory, Poppy put together a singing concert all by herself and organised a disco with family and friends to help raise awareness and funds.

MICK KNIGHTON MESOTHELIOMA RESEARCH FUND

The Mick Knighton Mesothelioma Research Fund (MKMRF) – now part of the British Lung Foundation – was established by Chris Knighton MBE in 2002. It was set up in memory of her husband, Mick Knighton, who was diagnosed with mesothelioma aged 59 after asbestos exposure in the Royal Navy.

MKMRF has raised over £1.5 million and funded five major research studies through the British Lung Foundation. Mesothelioma UK is fortunate enough to have had generous support from MKMRF since it first launched in 2004. MKMRF has shown great faith in what Mesothelioma UK tries to achieve and has supported us generously over the years.

Mesothelioma UK Head of Services, Liz Darlison commented: "While we are forever grateful to Chris and the MKMRF for the financial support they have given us, for me, the support is about so much more than money. MKMRF has given us their seal of approval, endorsed our vision and been such a moral compass and a boost for our whole vision. In the early days, when we were just building our charity, Chris was an amazing support to me personally and gave me the confidence to develop Mesothelioma UK."

Nurse funding

One of the biggest ways MKMRF supports us is by funding a Mesothelioma UK Clinical Nurse Specialist (CNS). Leah Taylor, CNS and team leader, works in the north east and her post is funded by MKMRF for three years.

Leah said: "Chris has been a tremendous support and a guiding light in helping me to develop the role within the north east, one of the worst affected areas in the UK. I feel very privileged to be working with the MKMRF and the BLF, and am grateful for their funding which allows me to help patients in this region."

Campaign partners

Over the years, Mesothelioma UK and MKMRF have stood together in a number of public campaigns including the two-year struggle to license Alimta (Pemetrexed) and make it available on the NHS. The two charities campaigned to reverse the policy of certain Primary Care Trusts to put an end to the postcode health lottery and make the chemotherapy drug available, no matter where you lived. Together, they helped to set up a Mesothelioma Charter, calling on the Government to increase funding for research and improve earlier diagnosis.

Chris Knighton (L) and Meso UK CNS, Leah Taylor (R)

Other projects to benefit from MKMRF

In 2012, MKMRF was the main funder of the first national tissue bank exclusively for mesothelioma in the UK. This new facility, known as MesobanK, supplies high quality tissue and blood samples and clinical data and brings together a national consortium of chest physicians, pathologists, thoracic surgeons, scientists and IT specialists.

Charity Partner of the Year

MKMRF continues to support Mesothelioma UK and was named as the Charity Partner of the Year at our awards night this year.

Chris Knighton said: "Liz Darlison and I first met in the very early days of Mesothelioma UK and the MKMRF. We came together with a shared passion to improve the lives of those with mesothelioma, with better care, treatment options and support for the both the patient and their carers.

"I am truly honoured and proud beyond words that Mesothelioma UK has awarded us their Charity Partner Award. This prestigious award means so much more as it's given by such a highly regarded organisation, dedicated to improving the lives of those suffering, both now and in the future, with mesothelioma. I hope that we can continue to work closely with Mesothelioma UK in the future."

MIMES – AN ARMED FORCES STUDY

As part of Mesothelioma UK's Supporting Our Armed Forces service, we've collaborated with the University of Sheffield on a research project that aims to identify the needs of mesothelioma patients who are, or were in the British Armed Forces.

The aims of this stage of the research are to:

- understand the experience and health/support needs of British Armed Forces personnel/veterans with mesothelioma (with and without exposure through the Armed Forces) and family carers
- identify how health professionals and support agencies within the Armed Forces and NHS can best meet the care and support needs of British Armed Forces personnel/veterans with mesothelioma

Those taking part will be contacted by a member of the research team who will discuss the study in more detail. Following this, a date for an interview will be arranged. This will take place on the phone, or at a place to suit the participant, and should last around 30 minutes. All responses will be anonymised.

The interview will explore views and experiences of the impact of mesothelioma for Armed Forces personnel/veterans. Topics that will be discussed in the interview through open and closed questions will include: understanding of the diagnosis, information and support needs, and the impact of a diagnosis.

If you would like to take part, you must be a person or family member of someone who:

1. Has worked or is working in the British Armed Forces
2. Is not experiencing physical or emotional distress that would be aggravated by participation
3. Is able to give informed consent
4. Can speak English

Please contact Beth Taylor at btaylor3@sheffield.ac.uk or Angela Tod at a.tod@sheffield.ac.uk or call the Mesothelioma UK helpline on 0800 169 2409 to register your interest.

MESOTHELIOMA UK
Supporting People With This Asbestos Cancer
MESOTHELIOMA UK SUPPORTING OUR ARMED FORCES

SIGN UP TO RECEIVE ARMED FORCES UPDATES

The Mesothelioma UK – Supporting Our Armed Forces service is aimed at veterans and Armed Forces personnel to help raise awareness about mesothelioma and signpost people to relevant information and support organisations.

Since starting the project in 2017, there have been some major developments including the appointment of a specialist nurse, a finance and benefits advisor specifically for Armed Forces personnel and veterans, and a number of new partnerships forged to provide a comprehensive, shared approach to supporting patients. A Facebook group has been set up for mesothelioma patients from an Armed Forces background to share experiences and journeys, and a comprehensive research programme, including the MIMES study, is also underway which will explore the effect of mesothelioma on Armed Forces personnel.

This is just the beginning and Mesothelioma UK would very much like to keep you informed about this service and key developments. To do this we have set up a regular 'Meso UK – Armed Forces Update' email. To allow us to send this update to you, please spare a minute to sign up at www.eepurl.com/dNoyfc

MAKING AN IMPACT IN WALES

In April 2017, Mesothelioma UK appointed a Clinical Nurse Specialist for Wales. Sarah Morgan became the 13th nurse to join the team and has made a big difference to mesothelioma patients in Wales.

Sarah works with colleagues across Wales to ensure that patients have access to specialist support and information, and to raise awareness of mesothelioma.

Sarah also promotes awareness about the options available for mesothelioma patients by supporting, signposting and disseminating information, leading and generally offering appropriate clinical support.

Sarah has been a nurse for over 30 years, originally training as a District Nurse and achieving her specialist practitioner qualification, then qualifying and working as a Specialist Palliative Care Nurse before becoming the first Lung Cancer Nurse Specialist in Hywel dda University Health Board (HDUHB) and setting up the service in 2008.

Sarah is a very active member of local and national strategic forums for developments in lung cancer and mesothelioma throughout the Welsh Cancer Network, having been chair of the All Wales Lung Cancer Forum (AWLCF) and presenting at the Welsh Thoracic Oncology Group (WTOG) & Welsh Pleural Interest Group (WPIG), and presenting at national and international professional conferences and meetings.

Sarah works as a Macmillan Lung Cancer Nurse Specialist for HDUHB in addition to her role as Mesothelioma UK CNS for Wales and is a founder member of the local charity - Lung Cancer Campaign - which aims to promote early diagnosis and improve services.

Commenting on her role, Sarah said: "The opportunity to work as a Mesothelioma CNS in Wales is a great privilege. As the only Mesothelioma UK nurse in Wales, I am committed to raising the profile of mesothelioma and influencing the development of specialist services across Wales."

Sarah has made great progress in raising the profile of mesothelioma in Wales and in 2018 organised an event with Vaughan Gething, Cabinet Secretary for Health and Social Services for the Welsh Government, as keynote speaker. The event put mesothelioma in the spotlight and raised £1,500 for Mesothelioma UK.

L-R Vaughn Gething, Liz Darlison, Baroness Delyth Morgan, Sarah Morgan

Sarah has forged strong links with local industrial disease lawyers such as J.M Parsons & Co, Thomson's Solicitors, who support Mesothelioma UK with fundraising efforts, and Hugh James solicitors who sponsored a highly successful national educational conference organised with Sarah for clinicians and professionals across Wales.

Working closely with the Welsh charity Asbestos Awareness Support Cymru (AASC) to improve patient support and information, Sarah, together with AASC, organised two very successful national events for patients and family this year. Action Mesothelioma Day was held in July and the first Annual Wales Patient and Carer Support Day in October.

As a committee member on the Cross Party Group of the Welsh Assembly Government on Asbestos, Sarah has been lobbying for mesothelioma patients to have greater access to trials in Wales. Following her presentations to the group raising the issue of inequity of access to trials for meso patients across Wales, Dawn Bowden, Assembly Member (AM) for Merthyr Tydfil and Rhymney asked a question in the House calling for greater support and commitment from the WAG for access to trials for patients in Wales.

Sarah has also been successful in bringing a new trial, ASSESS-Meso to West Wales and is the first Specialist Nurse to be a Principle Investigator of a research trial in Wales.

Sarah is particularly keen to establish an All Wales Mesothelioma Interest Group (WMIG) to ensure successful partnership working with healthcare professionals, support groups and other agencies, working with mesothelioma patients and families for the development of appropriate services for all mesothelioma patients across Wales. Through her efforts to raise awareness of the needs of mesothelioma patients, Sarah has gained much support for this project and this work will be a priority for 2019.

IMMUNOTHERAPY ISN'T FOR EVERYONE

By Dr Mags Portman

We are all different!!!

Today my kids have gone to school in odd socks. This is to celebrate diversity, as part of Anti-Bullying week. In the mesothelioma community, we are all united by a diagnosis of mesothelioma, but we respond very diversely to treatment.

I count myself as one of the lucky ones, because I have responded to traditional chemotherapy, whereas some don't. My tumour seems to be 'Platinum sensitive' as it shrinks really well (so far) when I have Cisplatin or Carboplatin.

For anyone who doesn't know my story, I was diagnosed with pleural mesothelioma in January 2017 and achieved almost a Complete Response following first line chemotherapy with Cisplatin and Pemetrexed. Rather frustratingly, I developed a cough plus night sweats only four months after completing this treatment. Disease progression was confirmed on a CT scan.

After talking to a number of consultants and considering options, I decided on second line chemotherapy with oral Vinorelbine. With this, I developed some interesting side effects, such as fevers on day 3-4, and quite severe pain of my chest wall. I hoped that this meant that the chemotherapy was 'doing it's job' but unfortunately it wasn't. I had further disease progression and stopped Vinorelbine after three cycles.

So what to do next? I knew about immunotherapy, in the form of PD-1 inhibitors, and how well some people, such as the lovely Mavis Nye, have done on these drugs. But I also knew that the evidence so far in mesothelioma comes only from small numbers of people. More evidence is needed regarding the efficacy (how well the drugs work) before they can be considered for use on the NHS. Currently, in the UK, the only way of accessing these drugs, such as Pembrolizumab or Nivolumab, is as part of a clinical trial or to pay privately.

When I was considering immunotherapy, the PROMISE trial was closing. Another trial, CONFIRM, which uses Nivolumab, has a placebo arm.

I felt that I wanted to be sure that I got the active drug, so ruled this out. I have a blog post discussing the issue of placebos here: https://notdoingthingsbyhalf.wordpress.com/2018/01/28/the-madagascan-periwinkle-affair/

So, reluctantly, I decided to pay for treatment with Pembrolizumab. But even though I had made this decision, it still did not sit comfortably with me for a number of reasons.

The main reason was, because I was accessing Pembrolizumab outside of a clinical trial situation, all the information about how well the drug worked in me, whether it improved my survival and whether I got side effects, wasn't captured. My data was not added to the body of evidence that may eventually lead to NICE approval for this and similar drugs in mesothelioma. It may as well have been flushed down the toilet and I'm not proud of that.

As it happened, despite initially feeling better on Pembrolizumab, it didn't work for me. We had hoped that the worsening appearance on scans was due to 'pseudoprogression' where there is inflammation associated with the drug in fact working... but it wasn't. I had continuing disease progression.

By the summer of this year, I was really very unwell. I had drenching sweats, severe fatigue and had lost a lot of weight. I felt as though I was dying. A conversation with my consultant suggested that I could go for further chemotherapy, but the likelihood of this improving the situation was very slim and it could actually hasten my decline. Along with the support of my husband, I decided to go for it! Now very 'treatment experienced', I started Carboplatin and Gemcitabine, my fourth line of treatment, in July.

I have recently completed six cycles, with very little in the way of side effects. And what a turn-around!! My cough has gone, the sweats have stopped, and I have so much more energy. I had a scan after three cycles which showed shrinkage of the mesothelioma, and further shrinkage after six cycles (apart from one small area which showed growth). I can't believe the difference in me when compared with the summer. I have got my life back and feel grateful every minute of every day!! I'm looking forward to a bit of time off treatment (I hope!), to allow my body to continue its recovery from the effects of chemotherapy. But I know how important it is to keep ahead of the game and have already begun to explore clinical trial options.

Mesothelioma UK has a great up-to-date webpage showing available clinical trials https://www.mesothelioma.uk.com/information-support/information/clinical-trials/

Here's to Christmas and beyond!!

A HUGE THANKS TO PAT STONE MESO SUPPORT

Pat and Graham Stone

Pat Stone Meso Support (PSMS) is a fund set up in memory of Pat Stone. Mesothelioma UK has received donations from PSMS which have provided the support necessary for Jo Hargrave's London-based Mesothelioma CNS post and enabled the charity to finance research and audit projects.

Mesothelioma UK is very grateful to Pat's husband, Graham, for kindly deciding to put Pat's settlement money into research and support for those affected by mesothelioma.

Graham tells the story of the fund...

Pat was a science teacher for over 20 years at an inner London grammar school and for most of the time, she taught Nuffield Sciences which involved a lot of hands-on lab work. She used Bunsen burners with asbestos mats and gauzes.

Although she was 71, Pat was fit and active, and was a trained bereavement counsellor with several local charities including St Christopher's hospice. However, in the autumn of 2013, she developed pleural effusion and was admitted into hospital. It was later established that she had contracted mesothelioma, resulting from exposure to asbestos.

We took legal advice but before it was settled, Pat died on 12 November 2014. In mid-2015, together with four of her close friends, we decided to use the settlement payment to try to improve the awareness, care and research of this cruel cancer which was not reducing, as had previously been projected. Cases unconnected with the heavy industries were now coming to light, such as teachers and even doctors.

We were fortunate enough to be introduced to Liz Darlison and Mesothelioma UK, and we had been aware that there were no specialised nurses in the London area for mesothelioma. We therefore committed our small charity to finance, for three years, a Mesothelioma Clinical Nurse Specialist in London. We have been lucky enough, with the help and encouragement of Mesothelioma UK, to arrange the appointment of a very committed Meso CNS, Jo Hargrave, now based at St. Barts.

With Pat's involvement with the hospice, we were aware that the two rooms allotted to counselling at St Christopher's were somewhat austere. Here again, we financed the total refurbishment of both rooms which now project a friendly and calm atmosphere.

In an effort to create a greater awareness of mesothelioma, we ran a full day workshop for over 40 delegates from all facets of health care. We enlisted a variety of speakers including three top London lung consultants, together with a specialist nurse and representatives of the hospice movement. We also included a coroner to speak on the legal aspects as mesothelioma is classed an industrial disease. Liz Darlison was there to inform the delegates of the help and advice available through Mesothelioma UK to patients, carers and family.

We also had a speaker from another voluntary charity giving help to those touched by this disease. It was a great and informative day.

As we wanted to do something constructive in trying to find the best way of diagnosing and treating mesothelioma, we financed a 12-month research study into one possible avenue of diagnosis. Amy Kerr's study looked at a non-invasive diagnosis method and her results will be published soon.

We are extremely grateful to Liz Darlison and Mesothelioma UK for the advice, encouragement and friendship they have shown us over the past three years. We have now spent every penny of the legal settlement in a way that I am sure Pat would have wanted and have closed our charity. I also believe that it has also gone some way to providing closure for me.

Liz Darlison, Head of Services for Mesothelioma UK added: "More recently PSMS donated further monies that have contributed toward Mesothelioma UK CNS Karen Lord's small scale study looking at Living Well with Mesothelioma and also an Organisational Audit of the Lung Cancer team. This latter Royal College of Physicians initiative will hopefully shed some light on how teams across the UK organise themselves to care for people with mesothelioma. It is early days for both projects but suffice to say, support from PSMS has been essential in getting them off the ground."

BRITISH LUNG FOUNDATION MESOTHELIOMA RESEARCH UPDATE

BLF's mesothelioma research network reaches first year!

Our Mesothelioma Research Network (MRN) is now one year old and thriving. The aim of the network is to drive research progress and improve outcomes for people with mesothelioma. We do this by connecting researchers together to share knowledge, skills and resources and stimulate collaborations.

In our first year, we have:

- Gained more than 100 members
- Sent two MRN e-newsletters and shared who is on the MRN, their skills and experience with all members
- Run the first ever MRN Research Day, with excellent delegate feedback
- Funded four researchers to attend the International Mesothelioma Interest Group (iMig) conference
- Found that 100% of MRN members would recommend joining to colleagues through our survey

In year two, we will offer more learning opportunities, stimulate research collaboration and allocate more funding to members. Researchers who work in the laboratory, clinical researchers and health professionals who treat patients with mesothelioma are encouraged to join via www.blf.org.uk/mrn

MesobanK goes from strength to strength

MesobanK continues to do well in recruiting people to donate their samples for research. The team is completing a steady stream of requests from researchers including the first requests from biotechnology and pharmaceutical companies. The first BLF-Papworth Mesothelioma Research Fellow has generated some exciting data on a potential new treatment for mesothelioma using gold nanotubes. This data, along with data from a BLF mesothelioma PhD fellowship, was used to support an application to the Engineering and Physical Sciences Research Council (EPSRC) by researchers at Cambridge University. These researchers were successful in gaining a huge £10 million grant to use technologies to develop treatments for three cancers including mesothelioma.

Mesothelioma stratified therapy trial (MiST): latest news

The MiST trial is a 'world-first' phase 2 clinical trial treating people when their mesothelioma has progressed after chemotherapy. It uses information about an individual's tumour to decide on the treatment given, an approach known as 'personalised medicine'. People taking part in the trial will also be asked if biopsy samples can be taken for testing while they are being treated. By doing this, the research team hope to be able to use detailed genetic analysis of biopsies to determine why some people respond better to treatments than others. The MiST trial has a complex design, there are four different 'arms' or groups that people will be allocated to, and each arm has different treatments. The trial has been specially set up, so it can be reproduced at different hospital sites. Due to the complexity of the trial set up, it has taken longer to open than anticipated. The MiST trial will be open to patient recruitment at four sites - Leicester, Manchester, Southampton and London - in January 2019.

The MRN, MesobanK and mesothelioma training fellowships and the MiST trial are supported by a generous donation to the BLF from the Victor Dahdaleh Foundation.

British Lung Foundation awards new mesothelioma research grants

We are thrilled to have awarded grants totalling £688,891 in our 2018 grant round.

Mesothelioma UK-BLF mesothelioma project grant
Dr John Maher, Kings College, London

Improving the power and safety of white blood cells that have been taught to destroy mesothelioma
Duration: 24 months
Amount awarded: £149,977
This project is funded by Mesothelioma UK and the grant-selection process, and monitoring managed by the BLF. More effective treatments are required for patients with mesothelioma. One approach involves teaching a white blood cell, called a T-cell, to recognise and destroy tumour cells. This is achieved by equipping the T-cells with a radar-like system, called a 'CAR' that can detect specific 'flags' produced by tumour cells. Blood is removed from patients and T-cells equipped with CAR. After two weeks of growth in the laboratory, the 'CAR T-cells' are re-injected into the patient. However, this treatment can cause severe flu-like side effects because a protein, known as IL-6, is overproduced when the CAR T-cells engage the cancer.

IL-6 also plays a role in favouring mesothelioma progression, by increasing tumour growth and creating an environment that 'switches off' the CAR T-cells, so that they can't attack the cancer. The research team propose to engineer CAR T-cells that can target

mesothelioma cells while simultaneously neutralising IL-6. In this project, they will use a CAR named 'T4' that they previously engineered. Alongside T4, the team will also engineer the T-cells to release a protein that blocks IL-6. They will evaluate the proposed approach (called RT4) both in the laboratory and in mice with mesothelioma tumours. An 'x-ray like' imaging approach will be used to track tumour growth in the mice, and changes in weight and blood tests will be used to detect side effects.

BLF mesothelioma project grant
Dr Robert Ladner, Belfast
Improving the efficacy of standard-of-care chemotherapy in mesothelioma
Duration: 24 months
Amount awarded: £185,498
One of the standard-of-care treatments for mesothelioma is pemetrexed, a chemotherapy. When cancer cells are treated with pemetrexed or similar drugs, they experience DNA damage that blocks their growth. Despite being standard of-care, most mesotheliomas become resistant to these therapies.

The team discovered that a protein known as dUTPase acts as a 'gatekeeper' to the cancer cell's DNA, protecting the DNA during treatment. Cancers typically have a high amount of dUTPase protein, giving the cancer cells a strong chance to survive and eventually overcome treatment with chemotherapy. This research proposal has one overarching goal: to provide scientific data to convince clinicians to direct dUTPase inhibitors toward mesothelioma patients where they have the potential to improve patient lives. To reach this goal, the team will test dUTPase inhibitors in various simulated chemotherapy treatments to improve their understanding of the vulnerability of mesotheliomas to these treatments. By analysing the cancer cells' molecular make-up, they will identify how this treatment kills mesothelioma cells. This could also enable them to identify any markers of vulnerability that may help to select patients who have the best chance of responding to dUTPase inhibitor treatment.

BLF-Mick Knighton Mesothelioma Research Fund mesothelioma project grant
Dr Robert Rintoul, Papworth
Development of patient-derived 'organoid' cell models of mesothelioma
Duration: 36 months
Amount awarded: £153,944
To learn more about how mesothelioma develops and grows, we need to develop new 'cell models' of this cancer. Until now, the research community has relied on growing cells as flat two-dimensional layers in plastic flasks. While useful, this does not reproduce the complex three-dimensional architecture of a tumour growing in the body. Recently, a new technology called 'cancer organoids' has been developed. Organoids represent small three-dimensional balls of cells. As part of the Human Cancer Model Initiative, the Wellcome Sanger Institute is working with Cancer Research UK, the US National Cancer Institute and the foundation Hubrecht Organoid Technology to develop organoid models in various cancers. The MesobanK team is partnering with them to take advantage of this brand new 'world-first' technology.

Samples of mesothelioma tumour from patients having operations will be used to develop and optimise robust methods for mesothelioma organoid development at the Sanger Institute, Cambridge. Each model organoid line will be carefully characterised to ensure that it closely represents the original tumour. Some of the models will be tested against a panel of cancer drugs to try to identify new treatment targets and 'biomarkers' of response. Once established, the models, along with the methods for developing the organoid and associated data, will be made widely accessible to researchers.

BLF-Mick Knighton Mesothelioma Research Fund mesothelioma project grant
Dr Daniel Murphy, Glasgow
Engaging the immune system to fight mesothelioma
Duration: 36 months
Amount awarded: £199,472
Immunotherapies have recently emerged as effective treatments for many cancers. These drugs act by revealing previously hidden cancers to the immune system or by activating immune cells directly to fight cancer. For example, drugs that disrupt the PD1 'immune checkpoint' system have shown great promise, but only work in around 20% of patients with mesothelioma. Macrophages are a kind of immune cell. They play a crucial role in establishing the chronic inflammation in the lining of the lung (pleura), which occurs before mesothelioma develops in most patients. Once mesothelioma is established, macrophages remain important, and make up 20-30% of all the cells present in human mesothelioma tumours. Recent studies also show that macrophages influence the immune response to cancer and may be involved in resistance to standard treatments.

The research team anticipate that macrophage treatment may be effective as a single agent and increase the number of responders to standard chemotherapy and/or anti-PD1 immunotherapy. They have also developed a new, unique, mouse model of mesothelioma to test their theories. In this study, researchers will inject macrophage treatments (CSF–1R or CD98 inhibitors) directly into the pleural cavity of mesothelioma-bearing mice. The team will then measure the effect of these treatments on the activity and death rate of the tumour cells, and the length of time the mice survive.

MESOTHELIOMA UK RESEARCH FUND

Earlier this year, Mesothelioma UK launched a special fund, dedicated to mesothelioma research and clinical trials. We'd ultimately like to be able to offer £1,000,000 each year to researchers looking into better understanding and treatment of the disease.

In addition to supporting researchers, the fund will also support our team of Mesothelioma Clinical Nurse Specialists who have a responsibility to ensure that they are aware of current research and trial opportunities so that they can inform patients.

So far, the fund has received **£11,250**.

Please contact us on 0800 169 2409 or email info@mesothelioma.uk.com for further information about donating to, or benefiting from, the research fund.

RECIPE - CHOCOLATE AND ORANGE POTS

This recipe is so easy to put together. You will end up with soft chocolate sponge on top and a rich chocolate and orange sauce underneath. Delicious!

Ingredients
- self-raising flour 200g
- cocoa powder 4 tbsp
- dark chocolate 100g, chopped
- golden caster sugar 200g
- butter 50g, melted
- egg 1
- milk 175ml
- oranges 2, zested

Sauce
- unrefined soft dark brown sugar 150g
- cocoa powder 3 tbsp

Method
1. Heat the oven to 180c/fan 160c/gas 4. Put the flour, cocoa, chocolate and caster sugar in a bowl. Mix together the melted butter, egg, milk, orange zest and stir into the dry ingredients. Divide the mix between 6 small ovenproof dishes (about 250ml each).
2. For the sauce, mix the sugar and cocoa, then divide between the tops of the puddings. Boil a kettle and pour approx 3 tbsp boiling water over each pudding. Bake for 20-25 minutes. You will end up with sponge on top and oozing chocolate sauce underneath.

If you are struggling with a poor appetite of weight loss, you can serve with crème fraiche, ice-cream or cream. If you are struggling with taste changes, you could top with extra orange zest for a more tangy taste. Don't forget to slice the zested oranges and either serve on the side or put in the fridge and have later - great if you suffer with a dry mouth.

Victoria Driver
Oncology Specialist Dietitian
East Lancashire Hospitals NHS Trust

MICK GEORGE REMOVES GAUZE MATS FROM SCHOOLS

Asbestos removal and disposal company, Mick George Environmental has recently completed a number of dedicated collections of potentially harmful Bunsen burner gauze mats from education facilities throughout Cambridgeshire, Lincolnshire and Northamptonshire.

The firm initiated the scheme following the recent announcement from the Department for Education (DfE) which instructed schools to remove the equipment after highlighting that it may contain dangerous asbestos that could cause harm to staff and pupils.

Traditionally the management of such substances comes at a significant cost, but as part of their commitment to relieve any threat from the material, Mick George Environmental conducted the collections for just £1 per gauze mat.

So far, more than £400 has been raised and the organisation will be donating all proceeds to Mesothelioma UK.

Hampton Gardens School and Arthur Mellows School in Peterborough, Boston College in Lincolnshire and Bishop Stopford School Isebrook School and Maidwell Hall School of Northamptonshire, were just some of the schools that had the mats removed.

Stephen Summerfield, Managing Director at Mick George Environmental commented: "The threat of asbestos is a real one and is something that Mick George Environmental take very seriously. We are pleased that some education providers took up the opportunity to let our experienced team manage the potentially harmful equipment safely.

"Over the years Mick George Ltd has successfully engaged in various safety initiatives with schools and this is just an extension of those partnerships already formed. We are keen to do what we can to relieve the severity of a situation such as this one.''

MICK GEORGE®

MORE SUPPORT FOR LANCASHIRE AND CUMBRIA

It is an exciting time for mesothelioma service developments in Lancashire and Cumbria. In addition to the adopted nurse posts for Joanne Darby and Karen Price featured on page 3 of this edition, a new patient and carer support group will be launched in Barrow in Furness on Monday 21 January 2019.

The Group will be called CLASAG (Cumbria and Lancashire Asbestos Support and Advice Group). The group will meet at the Barrow Disability Centre, School Street, Barrow in Furness, LA14 1EJ. The new support group will be supported by Disability First. Future meetings from January will take place on the third Monday of each month, from 1-3pm.

There has been a history of Asbestos Support Groups in Barrow. BARDS (Barrow Asbestos Related Disease Support) was the first support group and was set up with the assistance of Dr Helen Clayson, who worked as a general practitioner and a local hospice doctor, and witnessed the effect that mesothelioma was having on her patients. The group changed to CARDS (Cumbria Asbestos Related Disease Support) more than 10 years ago and was steered by Bob Pointer.

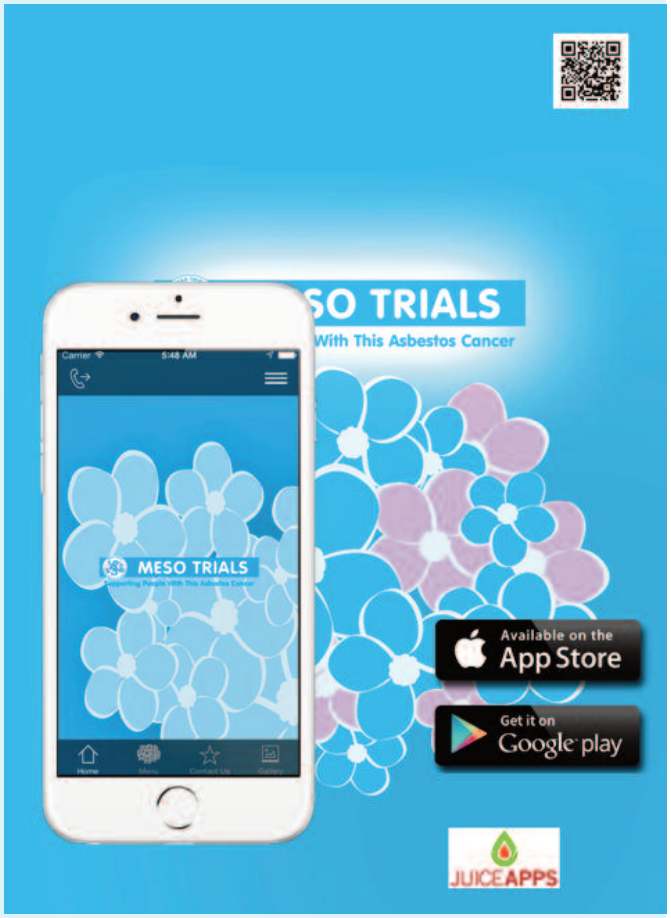
Bob is the son of a naval seaman who spent his childhood living in shipbuilding and naval towns in the south of England. After 14 years in the navy, Bob met his wife to be, Veronica and moved to her hometown of Barrow where he started work in the shipyard in 1985. This career change led to Bob realising the devastating impact asbestos was having on his fellow shipyard workers. Bob commented that "in the 1980s, it was everywhere - fire blankets, lagging, packing, cables and fuse boxes".

In 2005, Bob spearheaded a taskforce to set up a public meeting to discuss the impact asbestos was having on the town of Barrow.

Bob feels that everyone living in Barrow knows someone who has been affected by asbestos-related disease in some way - indeed, in his own cul-de-sac of only eight houses, four neighbours have it. Mesothelioma UK thanks Bob for all of his hard work and determination in keeping CARDS afloat and UK wishes the new group, CLASAG, every success in the future. The relaunch will emphasise the importance of this support for people and their families with mesothelioma, and other asbestos-related diseases.

The meetings will be informal and a speaker will be invited to each meeting to advise and assist on strategies to cope with illness and live life to the best potential. The networking will be vital and is often what people derive most benefit from.

CLINICAL TRIALS New clinical trials app for New Year



With every quarterly magazine, Mesothelioma UK provides a useful clinical trials update, bringing together information about all of the trials relating specifically to mesothelioma in the UK. It can be difficult keeping this information up to date as trials open and close, so Mesothelioma UK is working on the development of an app that will have all of this information available at the touch of a button on your phone or tablet.

The app will be updated in real-time as trials grow and change to keep doctors, nurses, patients and families as up to date as possible. The app will be available to download on Apple and Android devices and we hope to launch this early in the New Year so keep an eye on our social media for updates.

Fiona goes ATOMIC

Fiona Holmes was diagnosed with mesothelioma sarcomatoid in August 2017 and for the past 15 months has been taking part in the ATOMIC trial. She speaks of how thankful she is to be given this opportunity and of how her amazing fundraising campaign has not only raised money for research, but also awareness about mesothelioma. This is Fiona's story...

"In May 2017, I went to see my doctor with a pain in my side that was initially just thought to be a pulled muscle. Unfortunately symptoms continued, along with a persistent cough, and despite seeing five GPs in one month, I had no indication of the cause. A good friend who is a Cystic Fibrosis patient insisted that I walk into the Accident and Emergency Department at Addenbrooks Hospital, because she was so concerned about the sound of my cough.

"It was here within the first half hour that I heard the word mesothelioma. A few biopsies were taken and I was told to return in a week for the results. The biopsies returned inconclusive, my lung had reattached itself to its lining (which is unusual), but I was referred to Dr Robert Rintoul at Royal Papworth, an expert in this field.
I had my lungs deflated and large biopsies taken. A week later I was officially diagnosed with mesothelioma sarcomatoid.

"With this incurable aggressive cancer and a life expectancy of six months, I was left with a feeling of worthlessness. I was a healthy and fit 55 year old woman with a husband and five children. I had, at some time in my life, possibly during a period of employment as a hairdresser and beautician, been unwittingly exposed to asbestos and was now suffering the consequences.

"I was referred by Dr Rintoul as a suitable candidate for the ATOMIC trial and for the past 15 months have been travelling once a week to Bart's Hospital for the trial, under the supervision of Dr Peter Slozarek. The trial consists of weekly injections and of course, close monitoring. I still have episodes of pain but have had minimal issues with the trial and we were delighted to see a 70 per cent reduction in our latest eight-week scan.

"Obviously, since my diagnosis there has been an awful lot to absorb. There are many tiring visits to hospitals for tests and consultations, but behind all of the doctor's notes, the scan results and the meetings, is an ordinary person.

"I wanted to reach out to people to raise awareness about mesothelioma, what causes it and how it can affect anyone, with devastating consequences for sufferers and their families. When my good friend, Sarah Price who leads Ardeley Runners, approached me and said that she wanted to run Beachy Head Marathon for Mesothelioma UK, it was not only very touching for me personally but a very exciting process in which to be involved. So 'Team Fi xxx' was formed which comprised five runners and myself.

"Training for the toughest marathon in the UK commenced and the fundraising process in which I was heavily involved gave us a platform to raise the profile of mesothelioma amongst our friends. families and community. We have been astounded by the generosity and support we have been given. Fundraising for the marathon reached over £10k and further events including one at our village pub in Walkern have raised a further £2k.

"The opportunity of being on this trial has brought HOPE, HAPPINESS and ENTHUSIASM back into my life. To have been given extended time has enabled me to travel monthly and to spend time with my precious family and friends. We aim to go away for one week every month and our travels have taken us to Spain, Portugal, Iceland and Switzerland recently. I want to live as close to a normal, everyday life as I can.

"Throughout this process, I have been honoured to witness a NEW WORLD to me of people who I SEE dedicated to helping others. I know that my participation in the trial will not only impact me but the data will also help others as we search to find a cure for this disease.

"A BIG LIFE IN A SHORT TIME. EVERYONE SHOULD HAVE THIS RIGHT."

To donate to Fiona's fundraising, go to https://uk.virginmoneygiving.com/Team/TeamFixxx

SYSTEMS-2: A randomised clinical trial of radiotherapy for pain control in malignant pleural mesothelioma

Pain is a common symptom in mesothelioma and is notoriously difficult to control. Short courses of radiotherapy have been used to help alleviate the pain associated with this disease for decades, but until recently, we didn't know how effective this was. The SYSTEMS study demonstrated that a standard course of radiotherapy delivered over one week was clinically helpful for pain in about one third of patients. Importantly, patients experienced very few side effects.

SYSTEMS-2 is the first ever randomised controlled trial to assess the impact of radiotherapy dose escalation on pain control in mesothelioma. Within this clinical trial, patients receive either the standard course of radiotherapy (20 Gray) over one week or a higher dose (36 Gray), delivered over two weeks. Radiotherapy is targeted to sites of pain and sophisticated methods of radiotherapy planning and delivery are being used to ensure that side effects are minimised. Pain questionnaires, validated for use in patients with cancer, will be used to assess pain just before the radiotherapy and at weeks five and nine after treatment. Specifically, we will investigate whether one dose of radiotherapy is better than the other at controlling the pain. We will be also be assessing whether there is any difference between the groups in terms of quality of life, side effects and overall survival. A CT scan at week nine will determine whether the treated areas have changed in size.

SYSTEMS-2 opened in Glasgow in August 2016 and since then has opened at a further 11 sites around the UK: The Royal Marsden, Weston Park Hospital Sheffield, Guys and St Thomas, University Hospital Southampton, Belfast City Hospital, Southend University Hospital, Forth Valley Hospital, Norfolk and Norwich Hospital, New Cross Hospital Wolverhampton, Western General Edinburgh and Royal Shrewsbury Hospital. To date, 55 patients have been registered and 48 have proceeded to randomisation. Our recruitment target is 112 patients and we hope to achieve this by February 2020. A number of other hospitals are in set up and are due to open to recruitment shortly. These include St James Hospital Leeds, Churchill Hospital Oxford and The Christie Manchester.

For updates on trial recruitment and participating sites, as well as further information for clinicians and patients, please visit our webpage www.systems-2.co.uk or email miranda.ashton@glasgow.ac.uk

FIRST UK PERITONEAL MESOTHELIOMA CLINICAL NURSE SPECIALIST

Samantha Westbrook has been appointed as the first Peritoneal Mesothelioma Clinical Nurse Specialist in the UK. This new post has been funded by Mesothelioma UK and will be based at Basingstoke and North Hampshire Hospital.

Peritoneal mesothelioma is the less common form of the disease that causes the peritoneum (lining of the abdomen) to thicken and fluid to collect. This collection of fluid is called ascites and causes the abdomen to swell.

In her new role, Samantha will work alongside the Peritoneal Malignancy Multi-Disciplinary Team (MDT) to support, advise and signpost Peritoneal Mesothelioma patients and their families from across the UK. This will help to deliver the most effective treatment (including surgical options), care and awareness of available benefits.

Prior to joining Mesothelioma UK, Samantha worked as a lung cancer nurse for five years at Basingstoke and North Hampshire Hospital, dealing with oncology and pleural mesothelioma cases. Previously, she was based at Frimley Park Hospital in Surrey where she worked in Critical Care for seven years in a role that developed into being Practice Educator for the unit.

Commenting on her new role, Samantha said: "I'm bringing experience in critical care, lung cancer and oncology to this new role and am really looking forward to specialising in this particular area. Mesothelioma UK is all about the patients and my appointment will enable me to fully support peritoneal mesothelioma patients in a 'key worker' capacity to ensure that they get the best attention possible.

"I'm also interested in looking at the research side of the patient diagnosis and journey, and seeing how this data can help to influence my role and our approach to treating peritoneal mesothelioma over time."

Liz Darlison, Mesothelioma UK Head of Services, added: "Mesothelioma UK has been committed to doing all that we can to improve services and access to treatment and care for those affected by peritoneal mesothelioma. Appointing Samantha into this post is a major step that we are delighted to reach and we are so thankful for all the Mesothelioma UK supporters whose generation donations have made this possible.

"Samantha will be working closely with the charity's team of 20 nurses who are based all over the UK to ensure, regardless of where you live, if you are affected by peritoneal mesothelioma you will have access to the best treatment and care available."

To get in touch with the Meso UK nurse team, call our helpline on 0800 169 2409.

FUNDRAISERS

JURASSIC COAST CHALLENGE RAISES £674.23

My dad, Vic Oakman, was a hard-working man who worked as a carpenter and joiner.

Unfortunately, one of the first jobs he remembered doing was cutting sheets of asbestos for fire proofing. He loved to travel and was a great dad, grandad and great grandad. He was stolen from our lives by mesothelioma in 2016, aged 72.

In July, I took part in the Jurassic Coast Challenge and walked 50km in his memory, along with my husband who walked for MND, the disease that stole his dad the same year. We both wanted to do something positive to remember them and the great memories we have of them from before our lives were forever changed by their loss.

It was humbling to see people of all levels of fitness taking on this challenge, many to raise money for deserving charities. We are certainly no athletes, but we trained hard to make sure we did our dads proud! I was touched by the generosity of the people who donated to our fundraising, some of whom knew and loved dad, and some who were strangers, touched by his story.

Thank you for the work your charity does and I hope you continue to raise oodles more to help support more people like dad and families like us.

Annette Reeves

HALF TERM WITH A DIFFERENCE!

Chloe Parr, a primary school teacher, married Ryan Livesey, a maths secondary teacher, on Friday 26 October at the Norton Grange in Rochdale.

Chloe's dad, Richard, sadly died from mesothelioma in February 2011 and the bride was given away by her lovely mum, Lisa.

The bride and groom kindly made a donation to Mesothelioma UK to purchase Forget-Mesothelioma-Not trolley coins to give to each person who attended the wedding as part of their wedding favours and a further donation will be made following a sweepstake on how long the speeches would take.

Congratulations to both Chloe and Ryan, wishing you a long and happy life together.

FUNDRAISING EVENT RAISES £2,047.50 IN MEMORY OF ROBERT NEVIN

Thank you to everyone for your donations and will be forever grateful for your support. The fundraising was in memory of my beautiful dad who is greatly missed by us all and this charity (Mesothelioma UK) is wonderful!

Hayley

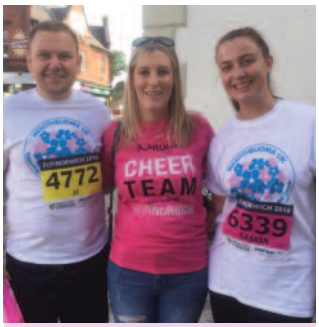
DEWSBURY ROCKERS MOTORCYCLE CLUB SUMMER DANCE 2018

On Saturday 28 July 2018 the Dewsbury Rockers Motorcycle Club held their annual summer dance at Six Lane Ends Club, Heckmondwike, West Yorkshire.

This year's chosen charity was Mesothelioma UK in memory of Graham Foster, known to many as Fozzy. Graham's family had already organised a cricket match last year and raised a fantastic amount of money from a sport he loved. As Graham was also a keen member of the Dewsbury Rockers Motorcycle Club and had been for over 50 years, the bikers felt it was only right to raise funds for Mesothelioma UK in memory of their friend.

Throughout the last year, monies have been raised through raffles and weekly domino cards, and by the end of the summer dance event, a fantastic **£1,035** had been raised. The group were very grateful to have Mairead Dixon, a Meso UK specialist nurse, join them for the presentation.

THE JACKSON FAMILY RAISE OVER £1.7K



Caption: (L to R): Joseph Jackson, Phoebe Osborne (Ashtons Legal & Anglia Asbestos Disease Support Group) and Saskia Vinnels.

Well done to Joseph Jackson and Saskia Vinnels who completed the Run Norwich 10k and raised **£**360 for the Mesothelioma UK/Anglia Asbestos Disease Support Group fund for a Meso UK nurse in Norfolk/Suffolk. Joe and Saskia decided to take part in the event after losing Joe's dad and hero, John Jackson, to mesothelioma in May this year after a 15-month battle.

The Jackson family has also generously donated a further **£1379.95** to the fund from the collection at John's funeral. Joe says: "The Norfolk and Norwich hospital doesn't currently have a dedicated Meso UK Nurse. We have raised this money in my dad's memory so that Norfolk/Suffolk people who are diagnosed with this terrible disease in the future will benefit from the expertise and support of a dedicated nurse."

The Norfolk/Suffolk nurse fund currently sits at **£6735.08** including Gift Aid. If you would like to make a donation, please go to: https://mydonate.bt.com/events/mesouknurse/452220

SWIM RAISES £527.50

I decided to do the swim in memory of my dad, Michael Brandon, who sadly passed away in 2014 after a long hard scrap, leaving behind my mum, Diane and my sister, Sue.

He taught me to swim and we used to visit the Solent area as kids so it was a fitting place and challenge.

It was a really well organised event run by lots of volunteer canoeists and sailors (for another fantastic cause) and I managed to make the crossing from Gosport to Ryde beach in 2h10m. The fish and chips tasted pretty good after the journey over.

Guy Brandon

TEAM MARVELLOUS - SUSIE LAYBOURN, LUCY CAISTOR, CAMILLA SHEPPARD - AMSTERDAM MARATHON

Team Marvellous – Susie Laybourn, Lucy Caistor and Camilla Sheppard – took on the TCS Amsterdam Marathon in memory of Susie's mum and keen marathon runner, Alison Regan who they lost to mesothelioma in August 2016.

Suzie, Lucy and Camilla raised a wonderful **£3,352.00**

5K PRETTY MUDDY CHALLENGE RAISES £2,170.68 IN MEMORY OF THEIR DEAR MOM AND NAN, JEAN

Jean's daughters, Jodine, Tracey, Claire and Paula, along with Jean's granddaughters, nieces and a few friends made up Team Jean and completed the Coventry & Warwickshire Pretty Muddy 5k in June.

We took part to raise much needed funds and awareness for a rare and extremely aggressive cancer called mesothelioma.

Our registration fees raised over **£300** for cancer research but we wanted all further proceeds to go direct to mesothelioma because on 2 August 2017, our Mom, Nan, Aunty & friend Jean was diagnosed with mesothelioma. We'd never heard of it until then.

Glenfield Hospital in Leicester is running lots of trials to try and find a cure for something that can really slow this cancer down and as yet, have not, but they continue to try. Mesothelioma is more common in men from working in areas that used asbestos, however mom had never worked with asbestos. We tracked it down to when she was 16, living in her parents' council house which was refurbished and had asbestos in the fire place. Months after the work had been done there was lots of thick dust all over the place and that's the only time that we believe she could have been in contact with asbestos.

Her father passed away from cancer on the outside of his lungs but mesothelioma wasn't a thing then, however we believe that he too died from this same cancer.

Since she was diagnosed in August, Jean faced many difficulties. She stayed positive and hopeful all along and started chemotherapy soon after diagnosis because of how rapid the cancer had spread. Chemotherapy was hard and made her unwell but she carried on regardless, having good and bad days along the way.

We then had the news that the chemotherapy had shrunk/slowed the cancer more than we had hoped and it all seemed good. Five months on the cancer came back, was more aggressive than before and had more than doubled in the area it filled.

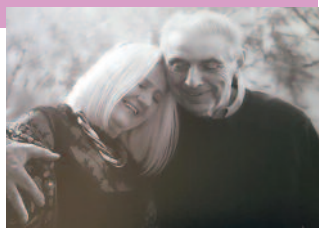
From a life where you are active to one where even walking from one room to another is difficult and you can no longer do the simplest of household chores as you have no energy and your breathing won't allow you. Where, in your mind, you can do everything you were doing just months ago but now your body won't allow you. All cancers are cruel but we have dealt with this first hand and it's cruel and harsh, and for such a rare and aggressive cancer we feel there should be so much more awareness and funding to try and find a cure.

It affected everyone who knew Jean, as well as us because she was such a wonderful lady with a huge personality who would do anything for anyone. It's hard and cruel, and we all want to do something to help. We are all struggling but Jean being the amazing, courageous and truly wonderful lady she was, she remained hopeful, positive and strong and still fought not to give in.

Jean sadly passed away on 21 May but she was with us all in spirit during the run.

Jodine Ashford & Team Jean

KEIMA RAISES £1,180 FOR MESOTHELIOMA RESEARCH IN MEMORY OF HER FATHER JAMES PAYTON



My father, James Payton, died of mesothelioma on 17 June 2018 - Father's Day, and whilst sad, was kind of perfect as he was the best father and grandfather anyone could wish for. The sad fact is that although he died at 77 years old, he could have had a decade or more of family life, experiences and love to enjoy but this precious time was stolen from him by this cruel disease.

Cancer is pants and it can affect anyone but mesothelioma is different - it wasn't the fickle finger of fate that determined that my brave, wise, funny dad would be stolen from our lives... no, asbestos fibres took a beloved husband, father and grandfather from us.

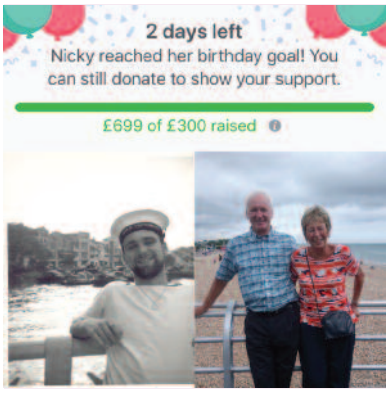
James Payton began an apprenticeship at the largest employer (by far) in Barrow-in-Furness at the tender age of 16. It was an achievement to earn an apprenticeship and he marked it by keeping his indenture papers all his life. He was a grammar school boy who could have gone to university but his father was ill of health and food was needed on the table. Those indenture papers, proudly signed by his mother, represented an opportunity to learn a trade and led to his becoming an engineer, a job he loved.

Governments and companies were aware of the devastating effects of asbestos and had been since the 1890s, but unfortunately, it wasn't banned. It was whilst working that he came into contact with asbestos. Barrow-in-Furness has the highest mesothelioma rates in the country, indeed, these rates pinpoint towns instrumental in shaping the ship building legacy of our industrial past.

I weep for our lost decade with dad, for all mum has lost, Glenn and I have lost, but also his grandchildren James, Jasmine, Louis and Emily. Dad didn't want tears - he wanted research into this brutal, pernicious disease and he really wanted a cure. We really wanted a cure. Dad started a medical trial during his treatment and it is hoped his experience on that trial will help shape treatment plans and help others but the brutal truth is that what he really wanted was to be with us all a little longer... he wasn't ready to leave and having him go has been the hardest thing to bear.

Keima Payton

FACEBOOK FUNDRAISING PAGE



For my birthday this year I set up a donation page on Facebook for Mesothelioma UK. My dad, Brian Holford, was diagnosed in July 2017 and since that day, the care he has received has been first class. From the Consultants at Queen Alexandra Hospital in Portsmouth to the specialist nurses like Anne, funded by Mesothelioma UK and HASAG. As a family we cannot thank you all enough for all you do and because of you my dad keeps on fighting.

We raised **£699** online and a further **£200** was sent directly to Mesothelioma UK, totalling **£899** and I only set out to raise **£300**!

Nicky Tandy

ZOE AND MATTHEW'S WEDDING

Zoe and Matthew Roberts celebrated their wedding and raised **£1,511.25** in memory of Zoe's dad.

My dad passed away on November 2017 after being diagnosed with the mesothelioma. The prognosis for mesothelioma is typically less than two years.

As both of us and so many of our guests work in the building trade, which has the most common chance of exposure, we feel it is pertinent to highlight the risks about asbestos and to support a great charity which offers advice and support to patients and families. They help with everything from support groups to clinical trials, and legal and financial advice.

Zoe Roberts

STEVE'S ANGELS

On 8 September 'Steve's Angels' took part in the Thames Bridges Trek, walking 25km across 16 London bridges, walking in memory of a wonderful dad, Grandpops and friend, Steve Gardner.

When my dad was diagnosed with mesothelioma he said "I will not give in" and he was true to his word, he never gave up hope, bravely going through nine cycles of chemotherapy along with radiotherapy and was willing to try any treatment.

Throughout his life he was extremely active, running countless 10ks and marathons around the world as well as being a proud 2012 Olympic and Paralympic Games Maker. He was a truly inspirational man, supporting others during the most difficult time in his life. With an engineering background and a love of 'bridges', this seemed the most fitting event to do in his memory along with raising awareness of a charity which is very close to our family's hearts.

The training beforehand definitely helped us on the day, the sun shone and the temperature was perfect for walking. We completed the walk in five hours exactly and raised a fantastic amount of money **£2,121,61**. A heartfelt thank you to everyone who supported us and donated. It was a day my dad would have loved.

Raising awareness of this dreadful disease is vital for the wonderful work Jill and all the team do at Mesothelioma UK.

As my dad would say "never give up." He will always be in our hearts and never forgotten.

Paula Bacon

MARILYN BAILEY, VERONICA HANSFORD, PEARL TUCK AND MARY RAWLINS

In memory of Richard – a sponsored horse ride on Studland Heath (and plenty of chutney and jam making by family members)

Our sponsored horse ride of all senior ladies, Marilyn, Veronica Pearl and Mary which included one who had never ridden before and took riding lessons especially for this occasion, took place on Studland Heath, Dorset, on 27 August – Bank Holiday Monday.

It took place to help raise awareness of the terrible effects of contact with asbestos and to contribute to the wonderful work that Mesothelioma UK is doing in the field of medicine and research which will hopefully help coming generations.

It took place in memory of Marilyn's husband, Reverend Richard Bailey, who was diagnosed in June 2016 with Mesothelioma and who died 10 months later, on 2 April 2017, aged 69 years. He had extensive contact with asbestos in his late teens when he worked as an apprentice carpenter.

Richard's Ministry as a Vicar and Chaplain, took him to South America, London, Liverpool, Shropshire, and Staffordshire.

The amount raised for the ride and also the making and selling of jams and chutneys by Richard's cousins, Pearl and Veronica, was a wonderful **£3,572.50**.

WARD 26 TEAM RAISES OVER £2,500

The wonderful thoracic surgical team on Ward 26 at Glenfield Hospital, Leicester, took part in the Asda Foundation 10km run in September.

They had set themselves a target to raise **£1,000** and ended up raising a fantastic **£2,517**!
Thank you all and well done.

PEN Y FAN CLIMB

The asbestos team at Irwin Mitchell Solicitors Bristol Office did a sponsored climb of Pen Y Fan, the highest peak in South Wales, on 30 September 2018. Unfortunately the view at the top was limited by the mist but the team managed to navigate their way back down again and were pleased to have been able to do something to help raise money and awareness for the fantastic support services provided by Mesothelioma UK.

Thanks to amazing support from friends and colleagues, the team managed to raise **£1,217.50**. In addition, the Irwin Mitchell Charitable Foundation has generously agreed to top up the donations received by **£365.25**, giving a grand total of **£1,582.75**.

Alex Lausen, Laura Wilkinson, Rebecca Buxton, Mandy Summers & Isabelle Selley

THE MANCHESTER 100KM

On Sunday 2 September 2018, Katrina London, Nick Jackson and Ed Joy from Irwin Mitchell Solicitors in Manchester raised money for Mesothelioma UK by cycling the Manchester 100km. The route started and finished at Wythenshawe Park and passed through Knutsford, Northwich, Winsford, Middlewich and Wilmslow.

The team completed the challenge in five hours and raised **£830**. Thanks to amazing support from friends, family and colleagues for their kind donations and to the lovely locals who were sitting on the grass on the final stretch clapping all of the riders across the finish line. A wonderful day for a great cause.

Run for Meso!

Looking for a running, walking or endurance challenge to help raise funds for Meso UK? We have places at a number of nationwide events.Look on our website or email jill.lemon@mesothelioma.uk.com for information.

IRWIN MITCHELL FUNDRAISING CHALLENGE

Having witnessed first-hand the devastating effect mesothelioma has on the lives of their clients and families, Alex Shorey and Erika Wright from the Irwin Mitchell Birmingham Office Workplace Illness team jumped (swam and climbed) at the chance to raise money for such a great cause.

In early September we took part in a Wolf Run and waded through waist-high mud, swam through lakes and scrambled across the forest floor to conquer the 10km course and raise **£460** for Mesothelioma UK.

Erika Wright

Losing weight? Be on time? Drink less? Eat less? What's your New Year Resolution going to be? Have you thought about regular charity giving? You could do something good today by signing up and supporting Mesothelioma UK. Please go to our website at www.mesothelioma.uk.com for more information.

THE INCA TRAIL TREK

In November 2017, we received the devastating news that my Dad, Peter, had mesothelioma and was given between two months and two years to live. Our family's world literally fell apart that day as Dad is, and always has been our rock. As with many who are diagnosed, we had never heard of this lung cancer but unfortunately, statistics show that there will be many more cases over the coming years. After attending a few of the Messy Support Groups run by Simon Bolton in Leeds, it was clear to me that more research needs to be done so this can be one of the many cancers in the future that can be managed without being terminal.

Myself and two friends, Nicky and Deone, therefore decided to raise money for Mesothelioma UK and completed a four day trek on the Inca Trail in Peru - completely out of my comfort zone as anyone who knows me is aware that I am a high heels and lip gloss kind of girl!! We raised just under **£2,500** which has been split between Mesothelioma UK and the local hospice who have been supporting my Dad as an outpatient. I am pleased to say that Dad had his 80th birthday in July this year and is still going strong.

Sarah Marshall

DAVE RUNS THE WORLD

Around 12 months ago, Dave Clissitt heard that his father, John, who had lived in Australia for 25 years had been diagnosed with mesothelioma. Dave visited his father during his treatment but sadly, John passed away in August 2018.

Dave hadn't heard of mesothelioma when his father was diagnosed with the disease and now, to pay tribute to John's brave fight, he's committed to raising awareness and hopefully raising money for research into funding a cure for mesothelioma.

Dave works for a trail running company and is self-funding a number of long distance endurance runs throughout 2019; challenges that he will document through his Facebook page - MyRun4Meso.

The runs are ultra marathons across the UK and internationally including the Brecon Beacons, Wales, Spain, Offa's Dyke and more, with the longest up to 630km. He'll be running up mountains, vertical climbs and other positive elevations during the courses. He's just returned from Spain after successfully completing his first challenge.

Commenting on his challenges, Dave says: "As an ex-Royal Marine and a member of a mountain rescue team, I've been running throughout my life to keep fit for mountaineering. I train every day and have a strict regime to prepare my body for limited sleep and to adapt to an appropriate nutritional programme.

"The challenges are a massive physical undertaking and I'm trying to ensure that I mitigate any risks of my body breaking down, but you never know. I dislocated my shoulder on my first challenge - the Snowdon trail challenge marathon - so hope for better fortune on these next challenges!"

To keep up to date with Dave's progress, follow him on Facebook at www.facebook.com/myrun4meso and please donate to help him towards his fundraising target of **£3,000** by sponsoring him at www.justgiving.com/fundraising/david-clissitt

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

Mesothelioma UK 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 or email jill.lemon@mesothelioma.uk.com

Corporate Donors

Bristol-Myers Squibb

Donation from Bristol Myers-Squibb

A huge thank you to the global biopharmaceutical company, Bristol Myers-Squibb, who kindly donated **£10,000** to Mesothelioma UK recently to help us to continue to support those impacted by mesothelioma.

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