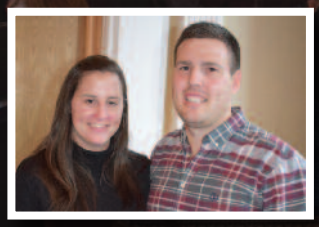
# MESOTHELIOMA MATTERS

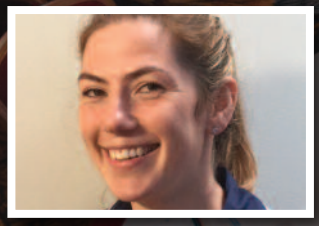
Winter 2019

## A successful Patient and Carer Day in Blackpool

Awards winners announced



The inspirational Chris Willis



New specialist nurse for Manchester

MESOTHELIOMA UK
Supporting People With This Asbestos Cancer

# PATIENT AND CARER DAY 2019

Our 14th annual Patient and Carer Day in Blackpool was an opportunity to meet others with similar experiences and learn about the latest mesothelioma research, treatment and care. Guests heard from speakers including oncology consultants, researchers, support groups and other patients sharing their stories.

Our Head of Services, Liz Darlison and Dr Jeremy Steele, Consultant Medical Oncologist at St. Bartholomew's Hospital chaired the morning session that opened with a brief talk on the history of the venue. The Imperial Hotel has accommodated many famous names over its 152-year history, from Dickens to Churchill.

The first speaker was Charles Pickles, who co-founded Lucion Environmental in 2002, which at the time of his exit from the company in 2019 was the UK's largest asbestos consultancy. Using his broad experience in the field and firm understanding of the risks and challenges presented by asbestos, Charles made a strong argument that the current advice needs to change, particularly in our public buildings such as schools where children are at particular risk.

Dr Catherine Henshall, Senior Research Fellow at Oxford Brookes University then presented the interim findings of a study, which was funded by Mesothelioma UK, into mesothelioma patients' experiences of follow-up care across three NHS trusts. The study aims to identify best practice for patient follow-up care to help them to lead fulfilling lives and 'live well' with their condition, with the intent to inform NHS trusts nationwide about providing comprehensive, high quality care for mesothelioma patients (You can read more about this study on page 6 of this magazine).

Tracey Wood, founder of the Glynnis Gale Foundation, which supports mesothelioma patients and carers in Southern Africa, told the story of her mother, after whom the foundation is named. Tracey described a recent visit to South Africa to meet patients, carers and healthcare professionals, and the foundation's aim to build a hospice.

Professor Dean Fennell, Consultant Thoracic Medical Oncologist and one of the leading authorities on mesothelioma clinical trials in the world, gave an update on clinical trials in the UK and worldwide. He included an insight into the recent results of the PROMISE-meso trial, which found that patients receiving pembrolizumab immunotherapy for malignant pleural mesothelioma did not experience longer overall survival or progression-free duration, which was presented at the European Society of Medical Oncology (ESMO) Congress 2019 in Spain.

Professor Fennell reiterated the words of lead study author, Professor Sanjay Popat of the Royal Marsden Hospital, that while pembrolizumab was not superior to chemotherapy, survival times were similar, suggesting immunotherapy might offer an alternative to chemotherapy.

Dr Noelle O'Rourke, Consultant Clinical Oncologist in Glasgow, which has the highest incidence of mesothelioma in the UK, spoke about radiotherapy options in the care of mesothelioma. The resounding message of her presentation was that unfortunately, mesothelioma is not a well-known cancer in the broader healthcare community so mesothelioma patients need to be 'selfish' and ask about treatment options. Get as much information as you can. Call the Mesothelioma UK information line and speak with one of our clinical nurse specialists. The rallying call, "don't be afraid to ask!" was met with enthusiastic applause by an audience that clearly understood the importance of that message.

Dr Kathryn Gaunt, Consultant in Palliative Medicine, and Sister Natalie Barnett, Lung Cancer Clinical Nurse Specialist, introduced palliative care and gave personal insight into the way in which this service is delivered in the East Cheshire NHS Trust.

After lunch, Dr Avinash Aujayeb took over from Dr Jeremy Steele to chair the afternoon session with Liz, which changed from the published programme.

Before the first speech, Liz presented the Smedley Family with their award for Team Fundraiser of the Year in recognition of their amazing contribution to the charity. This included two fundraising events that raised a total of £42,000 and an introduction to JDR Cables, which made Mesothelioma UK its charity of the year for 2019.

Liz then presented Chris Willis with his award for Most Inspirational Fundraiser of the Year, a well-deserved award as Chris then opened the afternoon session with a powerful telling of his journey with mesothelioma. He started with a period of symptoms that were diagnosed as everything from a poor diet to hernia, which resonated with many in the room. He was finally referred to Guy's Hospital for confirmation of the mesothelioma diagnosis, where, he said, "I met the amazing Rachel Thomas," Mesothelioma UK Clinical Nurse Specialist. Chris said, "I couldn't even pronounce it, let alone know what it was."

He spoke honestly about the emotions that he and many patients feel including guilt and fear, and how counselling helped. Ever thinking about others before himself, Chris said, "I always say it's a lot harder on your loved ones than it is on the patients."

Chris has just been informed of a new tumour in his pelvic area and is due to return to Guy's but is currently well, continuing to work as a primary school teacher and making the most of every day with his wife, Evelyn. His speech touched every person in the audience and he left the podium to a spontaneous standing ovation. Thank you to Chris for sharing his story, which you can read in full on our website.

Jennifer Seavor, Senior Associate with Royds Withy King, gave the audience an insight into the current UK status of medicinal cannabis and CBD oil, which has seen a massive growth in interest in the UK for treatment of a variety of medical conditions, reiterating Noelle's earlier call to action, "don't be afraid to ask!".

Professor Angela Tod and Dr Stephanie Ejegi-Memeh from the University of Sheffield then gave a summary of patient and carer research including the RADIO Meso, MORE and MiMES studies and a wealth of other research being conducted around the UK that aims to provide evidence-based recommendations to healthcare professionals.

They were followed by Lorraine Creech, Mesothelioma UK Clinical Nurse Specialist Team Leader, who provided additional details on the Mesothelioma Outcomes, Research and Experience (MORE) survey, which invited patients to describe their experience of investigations, treatment and care. 652 surveys were distributed, 510 were returned and 505 were validated by our Clinical Nurse Specialists, which will now be analysed.

The survey will enable Mesothelioma UK to inform healthcare providers about what is being done well, what could be improved and where there are variations in treatment and care.

It will also help Mesothelioma UK to develop its services to complement those of the NHS. Mesothelioma UK will make recommendations representing the patient experience and circulate these to the wider mesothelioma community and healthcare providers.

Liz closed the event with an introduction to Mesothelioma UK's team of clinical nurse specialists, who really are the charity's 'tour-de-force' as described by a senior consultant.

The annual Patient and Carer Day is a chance for those affected by mesothelioma to meet each other, share stories, ask questions and hear from healthcare professionals.

Thank you to all of our speakers and guests for making this one another valuable event. We've tentatively booked Southampton for the 2020 event, so please keep an eye on our website where you can join our email list and follow us on social media to be the first with the details.

# A NIGHT OF AWARD WINNERS

Hurricane Lorenzo seemed to make landfall just as our guests were leaving the hotel to enjoy a drinks reception on a heritage Blackpool tram, sponsored by Royds Withy King. This gave the illuminations a particularly special 'glow'. Braving the rain and somehow all still managing to look glamorous, guests then took their places in the Ballroom, with its ornate ceiling, for dinner interspersed with dance demonstrations by an award-winning Latin American dance couple.

The highlight of the evening was the presentation of awards to fundraisers, donors and others who have had a significant impact on Mesothelioma UK in the last year.

## CORPORATE DONOR OF THE YEAR: ROYDS WITHY KING

The law firm, Royds Withy King is a Gold Donor to Mesothelioma UK in 2019-20 and is often the first to respond to any requests that we may make to support specific events.

## SPECIAL CONTRIBUTION OF THE YEAR: LINDA LAKIN

This award was especially poignant for the operations team as Linda was a regular volunteer in the office and had made many friends by volunteering at previous patient and carer days. Linda passed away in December 2018 and her husband and daughter received the award. You can read Linda's story and her husband Jerry's story on our website.

## FUNDRAISER OF THE YEAR: JAN MASON

Jan won Fundraiser of the Year as she pledged and committed herself to raising £20,000+ to support a nurse for a year. She has taken part in many fundraisers over the last couple of years and the last and final event was cycling from John O'Groats to Lands End, which then took her final total over £20,000.

## TEAM FUNDRAISER OF THE YEAR: THE SMEDLEY FAMILY

Liz presented the Smedley Family with their award at our Patient and Carer Day.

The other highlight of the evening was the Cha-Cha masterclass! Led by the professionals, our guests swayed their hips and moved their feet so well that even Craig Revel Horwood would have said, "three words: Fab-u-lous!"

Thank you to all of the organisations who bought tables and provided some amazing raffle prizes, to the sponsors of the drinks reception and first dance demonstration, Royds Withy King, and the sponsors of the second dance demonstration, Thompsons Solicitors, and to everyone who attended to make it a special celebration of the work of Mesothelioma UK.

## CHARITY PARTNER OF THE YEAR: HASAG

HASAG is a charity dedicated to helping people suffering from asbestos-related diseases and their families throughout the south of England, south east, London and Home Counties. Our two charities have worked closely together for many years. Liz commented that: "we think the same, we feel the same and we want the same for our patients and carers."

## JUNIOR FUNDRAISER OF THE YEAR: LIZZIE MILES

At the age of just 14, Lizzie cut off her long locks in a sponsored 'brave the shave', to not only raise money for Mesothelioma UK but also donate her hair to the Little Princess Trust, which provides real hair wigs free of charge to children and young people who have lost their own hair due to cancer treatment and other conditions. Lizzie's fundraiser was in memory of her grandfather, who died of mesothelioma in 2011.

## MOST INSPIRATIONAL FUNDRAISER OF THE YEAR: CHRIS WILLIS

You can read about Chris on page 13 of this magazine and read his full patient story on our website.

# CALL FOR JUSTICE AND EQUALITY OF CARE FOR PATIENTS TREATING THEMSELVES WITH CANNABIS

In November 2019, a new patient advocacy organisation called Cannabis Patient Advocacy & Support Services (CPASS) launched at The Royal College of Nursing (RCN).

In 2018, the UK Home Office and Department for Health and Social Care took the decision to legalise and regulate cannabis for medicinal use. The Royal College of Nursing (RCN) has proactively sought to support these changes. CPASS will focus on support and care for patients considering cannabis for medicinal treatment and their carers.

CPASS will champion the rights of patients, parents, carers and nurses, offering advocacy, training and education as well as support guided by an advisory board of expert clinicians across all pertinent disciplines and patient ambassadors.

Medicinal cannabis is being considered by the medical community for conditions such as drug-resistant epilepsy, MS, neuropathic pain and chemotherapy-induced nausea and vomiting, and many leading researchers have shown indications of broader use beyond these conditions.

For all of these chronic conditions, nurses are at the centre of patient care. CPASS is calling out to clinical nurse specialists, offering support and training to be able to deliver the best care for patients. Patients considering medicinal cannabis will have a platform to ask questions specific to their conditions, and also raise concerns they may have over how to use CBMPs. CPASS aims to offer non-judgemental and confidential advice for patients to alleviate concerns over safe consumption and how to use medicinal cannabis and have published a Patient Guide which you can register for and download from their website at www.cannpass.org

CPASS will be developing accredited educational tools for front-line healthcare workers and professionals, whilst fostering a supportive network of nurses and carers to help them discuss and guide patients about medicinal cannabis.

## LIZ HONOURED BY HER MAJESTY

Following the announcement in July that our Head of Services, Liz Darlison, was to be awarded an MBE in the Queen's birthday honours list, Liz recently attended an investiture ceremony to receive her MBE. On 21 November 2019, Liz attended Buckingham Palace where she was presented with her MBE by Her Majesty the Queen. Liz received her MBE for services to cancer research and patients, and said that it was a huge honour, not only for her but for Mesothelioma UK and the University Hospitals Leicester NHS Trust where she works as a Consultant Nurse.

## SARAH'S NURSE OF THE YEAR AWARD

Our Mesothelioma Clinical Nurse Specialist for Wales, Sarah Morgan, was honoured recently at the Royal College of Nursing in Wales Nurse of the Year Awards. On 13 November 2019, at the ceremony in Cardiff, Sarah was awarded the Advanced and Specialist Nursing of the Year award. The award recognised Sarah's success in creating a new nurse-led Rapid Access Lung Cancer clinic. This model of care is now being spread and scaled across Wales.

# UPDATE ON MESOTHELIOMA TREATMENT PATHWAYS STUDY

**Project title:** Exploring clinical decision-making in mesothelioma treatment pathways across three NHS Trusts: a mixed methods study
**Principal Investigator:** Dr Catherine Henshall
**Study duration:** 01.10.19 to 30.09.20

The study's aim is to develop a collaborative, evidence-based, patient-centred approach to mesothelioma clinical decision-making across three NHS Trusts: Oxford University Hospitals, Royal Berkshire and Buckinghamshire NHS Foundation Trusts.

Objectives to be compared across three trusts are:

- Guidelines, policies and processes exist to inform clinical decision-making in relation to mesothelioma treatment pathways, how closely they align and why
- Factors influencing multi-disciplinary team decision-making in mesothelioma treatment
- Clinicians' awareness of/engagement with mesothelioma research and how this informs practice
- Current and potential strategies for improving clinician engagement with mesothelioma research

The study will involve:
1) accessing the records of mesothelioma patients treated at the three Trusts over five years (n=220) to collect data on diagnoses, treatments, survival rates and clinical care teams
2) collecting local and national documents relating to mesothelioma patients' treatment pathways
3) focus groups with lung-cancer multidisciplinary team members at each Trust to explore how much research is embedded in clinical decision-making and how the multidisciplinary team and other clinical factors influence decision-making in mesothelioma care.
Findings will compare similarities and differences between the Trusts' and produce recommendations to promote shared knowledge and collaborative, evidence-based, clinical decision-making.

The study proposal is currently being reviewed by the NHS ethics committee and will begin once ethical approvals are in place.

# THE LEGACY OF ASBESTOS TOLD THROUGH A NEW PLAY, FIBRES

Fibres is a play that tells the story of a Glasgow couple, Jack and Beanie, diagnosed with mesothelioma as a result of Jack's work in the shipyards and Beanie washing his asbestos-covered clothes. The play toured Scotland in October and used both humour and shocking frankness to tell the story and engage the audience.

The play is co-produced by Stellar Quines Theatre Company and Citizens Theatre. Writer, Francis Poet, wanted "to write a real human story, with love and laughter as well as a tragedy."

It's good to see mesothelioma and the dangers of asbestos being highlighted in this way. Congratulations to all involved on a successful play about a difficult topic.

# MESOTHELIOMA UK TO ATTEND IMIG 2020 IN BRISBANE

The 15th biennial International Mesothelioma Interest Meeting 2020, which takes place in Brisbane, Australia, will be attended by members from Meso UK's Clinical Nurse Specialist team. It is an opportunity to discuss the most up-to-date research and diverse topics of interest with leading experts in asbestos-related cancer. Attending this conference will aid the understanding of mesothelioma and advance developments towards a cure and prevention of the disease.

iMig international Mesothelioma interest group

# LUCION SERVICES ANNOUNCES 10TH ANNIVERSARY OF ASBESTOS MANAGEMENT CONFERENCE

For the past decade, market leader in asbestos inspection, testing and consultancy, Lucion Services, has hosted the UK's largest asbestos management conference. Each year, the conference brings together industry leaders in all sectors to share best practices when managing their asbestos risks, and promote the use of preventative controls to protect individuals and environments.

This year, the Asbestos The Truth conference will be returning on **14 May 2020**, hosted by the University of London at its world-renowned events venue, Senate House.

To mark the 10th anniversary of the conference, Lucion reflected on feedback from delegates over the past 10 years. This year, the organisation will be moving away from telling delegates why they should manage asbestos risks, and instead, the focus will be on a step by step walkthrough of ***how*** to effectively manage the risks from start to finish.

The conference will be digging deep into the detail, inviting speakers from both Mesothelioma UK and Lucion Services to talk about how best practices and effective training is essential to preventing further exposures. Lucion will be highlighting case studies of its top clients who have changed their hazards from red to green, and continue to hit the mark when it comes to managing risks and protecting individuals from asbestos exposures.

Lucion will be taking delegates through the options of how to manage their asbestos risks, assessing options of managing asbestos in-situ and removal, highlighting the importance of proactively managing asbestos risks and achieving compliance with the Control of Asbestos Regulations (CAR) 2012.

Asbestos exposures are preventable when the correct course of management action is taken. The costs of getting asbestos management wrong can be substantial and pose unnecessary, avoidable risks to building occupants and those involved in any site works.

Meso UK will be working closely with Lucion in the months leading up to the conference on promoting awareness of the dangers of asbestos exposures to industry professionals across multiple sectors.

# MY MESOTHELIOMA CARE PASSPORT

The planned care that you receive following a diagnosis can mean that there's a lot of information, dates, medical information and contact details to remember. We've recently developed a pilot project - My Mesothelioma Care Passport - to help with this. It's a pack designed to help patients stay up-to-date with the planned care that they have discussed and agreed with their healthcare professionals.

The passport is a concise record of your care to date, helping you to understand and discuss it with anyone you choose. It can be used to store contact details, appointment times/dates, x-ray and scan reports, clinical letters, prescriptions and anything else related to your care. The passports are available from healthcare professionals and can also be downloaded from our website at www.mesothelioma.uk.com/passport. There's also a feedback form on the website for patients to let us know what they think of the passport so that we can make improvements where necessary.

# 20TH ANNIVERSARY OF THE UK ASBESTOS BAN

This year marks the 20th anniversary of the UK's ban on asbestos. However, since its ban in 1999, more than 85,000 Britons have died from mesothelioma and asbestos-related diseases. The reason for the continued number of cases, despite the ban, is because it can be decades after exposure before symptoms appear.

In 2016, there were 2,595 deaths from mesothelioma, a 10% increase since 2010 (2,360) despite predictions that the national epidemic would peak at 2,040 per year by 2016. Because the asbestos ban did not require the removal of asbestos-containing products, most of the asbestos used in the country during the 20th century remains in place in buildings built before the ban. This includes many hospital buildings and schools which could account for emerging data showing patients from occupations which are not traditionally associated with asbestos e.g. healthcare workers and younger patients who could have been exposed at school.

In 1999, asbestos-related diseases were still a little-known topic and mesothelioma was virtually unheard of among the general public. Thankfully, over the last 20 years, the campaigning efforts of mesothelioma charities and asbestos victims' groups have highlighted the dangers of exposure to asbestos and raised awareness of it nationally.

Initiatives such as Mesothelioma UK's Action Mesothelioma Day, the annual Parliamentary Asbestos Seminar, meetings of asbestos victims' groups and the Parliamentary Asbestos Sub-Group, asbestos campaigners and victims' groups are crucial in raising awareness among the general public, employers and policy makers.

There is still a long way to go. However, progress is being made. The UK Mesothelioma Alliance (UKMA), formed in 2017, brings together mesothelioma stakeholders as one voice to raise awareness.

A spokesperson for UKMA said: "The work of asbestos charities such as Mesothelioma UK, the June Hancock Mesothelioma Research Fund, the John Pickering Trust, the Mick Knighton Mesothelioma Research Fund and the many support groups such as HASAG, not only raise vital funding for research but also provide signposts for patients and their families to access the medical, practical, legal and moral support that they deserve.

"UKMA members are working to ensure equitable access to treatment and care throughout the UK, and raise awareness of mesothelioma to increase early diagnosis and reduce exposure to asbestos."

Much progress is being made in terms of scientific research, clinical trials, compensation for exposure, support networks and access to clinical experts.

- Mesothelioma UK now has 25 clinical nurse specialists posted around the country
- There are around 20 clinical trials currently active in the UK (as at 6 November 2019)
- Government compensation packages for those who can't trace a liable employer of around £123,000 are available
- There are 30 mesothelioma support groups for patients and carers around the country and 13 groups for asbestos-related disease support

# NEW REPORT SAYS 'UK IS FAILING TO BRIDGE THE ASBESTOS SAFETY GAP'

A new report citing evidence of the hidden health risks posed by asbestos in UK public buildings, such as schools and hospitals, has been launched by the independent think tank, ResPublica. The report – Don't breathe in: bridging the asbestos safety gap – reveals that the most toxic forms of asbestos account for 98 per cent of UK mesothelioma deaths, yet are virtually invisible to current UK monitoring technologies, leading to increased mortality in professions not normally associated with asbestos.

It draws on evidence of a rise in mesothelioma deaths among British teachers and nurses, who are respectively five and three times more likely to develop the disease.

Furthermore, the levels of airborne asbestos currently deemed acceptable under the Health and Safety Executive's (HSE's) regime means that a British schoolchild could breathe in 10 times more asbestos per day than a schoolchild in Germany.

Included in the report's recommendations are that:

- Government should bring the current H&S regime up to par with Germany, France and the Netherlands
- Government should commission a cost-benefit analysis for the prioritised, phased removal of all asbestos from public buildings in the UK
- Government should provide HSE with more resources to revise and clarify the current 'Duty to Manage', given the practice and evidence that has emerged showing that complexity works against compliance
- Establish a central register of all asbestos currently in place in public buildings across the UK
- Include the occupations of mesothelioma victims above the age of 75 to reflect the link between workplace hazards and the national death-rate
- Improve the regime for reporting disturbance of asbestos materials in a way that reflects the true risks that this poses to schoolchildren

You can find a copy of the full report at www.airtightonasbestos.uk/research

# LADIES' LUNCH 2020 – SAVE THE DATE

Following the tremendous success of the Mesothelioma UK Ladies' Lunch in 2019, we are pleased to announce that the event will return in 2020.

The Lunch will take place on Friday 6 March at the Manchester Macdonald Hotel, which is situated next to Manchester Piccadilly train station. It is a chance to celebrate International Women's Day and meet others affected by, or working in the field of mesothelioma. There will also be an update on the Gendered Experience of Mesothelioma (GEM) study which looks at the different experiences of men and women (see more information on page 10 of this magazine).

Lorraine Creech, Mesothelioma UK Clinical Nurse Specialist Team Leader said: "We all had so much fun at our last Ladies' Lunch. The vibe in the room was so delightful with everyone having fun, raising funds and awareness of mesothelioma. Please come and join us in making mesothelioma matter."

# LAW FIRM HOLDS ANNUAL STUDY DAY

Hugh James has announced the date for its study day in 2020, following the success of previous annual events. Next year's study day will take place from 9am to 4pm on Friday 19 June 2020 at Hugh James, Two Central Square, Cardiff, CF10 1FS. The firm has attracted world-leading speakers in previous years and the line-up for next year's day will follow soon. If you would like to reserve a place at the study day, please contact Hjconference@hughjames.com

# ANGLIA ASBESTOS DISEASE SUPPORT GROUP RECEIVES PRAISE

Mesothelioma UK would like to acknowledge the hard work of a group of volunteers, led by Mesothelioma UK Ambassador, Brian Wallis. Brian and his volunteers from Anglia Asbestos Disease Support Group (AADSG) raise awareness of the charities and the Armed Forces project in particular, at various events across the east of England.

This year, they have attended over 30 events to raise funds and awareness, and since 2015, the small group of volunteers have raised over £8,000. In addition to this, the group has raised over £3,000 at support group meetings that take place monthly at five different locations across the east of England.

AADSG has also raised considerable funds towards the future placement of the region's second Mesothelioma UK specialist nurse.

Other support groups, along with mesothelioma patients, are welcome to attend their various meetings and full details can be found at www.angliaasbestos.co.uk

# THOMPSONS SOLICITORS MARKS ACTION MESOTHELIOMA DAY 2019

On 6 July 2019, colleagues from Thompsons offices around the country attended various events to mark and commemorate those affected by mesothelioma, including a butterfly release at MESothelioma Support Yorkshire (MESSY), cake sales at LASAG, and numerous memorial events.

All events were well attended, and brought people together to remember their loved ones and everyone affected by this asbestos-related disease in a very positive environment.

Thompsons would like to thank everyone involved in organising such fantastic tributes to those who have paid the ultimate price through their exposure to asbestos.

# CLINICAL TRIALS AND STUDIES

## GEM LOOKING FOR PARTICIPANTS

Consultation with health and legal professionals indicates that women may have a different experience to men regarding mesothelioma in terms of awareness of the disease, diagnosis, access to treatment, and compensation and legal processes. There are many possible explanations for this but little research to establish what is actually going on.

Gendered Experience of Mesothelioma (GEM) is a Mesothelioma UK collaborative study supported by generous donations from 12 King's Bench Walk, HASAG, Irwin Mitchell, Papworth Mesothelioma Social Group and Royds Withy King. GEM is being conducted by the Mesothelioma Patient Experience Research Group at the School of Nursing and Midwifery, University of Sheffield. The study is now seeking patients who received a mesothelioma diagnosis more than six months ago and who would be able to take part in a telephone interview.

The study aims to explore the experiences of men and women with mesothelioma, their family carers, as well as the various staff with whom they come into contact. Researchers will seek to understand why any differences that are identified occur. The goal is to establish how services should best be delivered to be accessible and acceptable to both men and women.

If you have been diagnosed with mesothelioma more than six months ago and would be able to take part in a telephone interview, please email info@mesothelioma.uk.com or call free phone 0800 169 2409 for more information and to be put in contact with the research team.

## RECRUITING FOR NEMO AND BEAT-MESO

Two clinical trials, Nemo and BEAT-Meso, are recruiting patients. Open centres for **NEMO** in the UK are Wythenshawe Hospital, Manchester, Royal Marsden Hospitals, Chelsea, Sutton and Kingston, Weston Park Hospital, Sheffield, South Tyneside District Hospital, South Shields and Mount Vernon Hospital, Middlesex. Please see the enclosed clinical trials table for more details or visit www.mesothelioma.uk.com

The **BEAT-Meso** clinical trial is open at the Royal Marsden Hospitals (Chelsea and Sutton), and Truro Hospital. Sites will also be set up at Maidstone, Sheffield, Guys, Addenbrookes, Plymouth, Clatterbridge and Wythenshawe.

The team is looking for newly-diagnosed mesothelioma patients to take part.

Patients should speak to their oncologist about a referral for clinical trials.

# HEALTHCARE WORKERS AND MESOTHELIOMA

A new research study is looking for mesothelioma patients who are/were healthcare workers. The Healthcare Worker Mesothelioma Asbestos Guidance Study (MAGS) is looking for participants. If you have been diagnosed with mesothelioma and you are, or have ever been a healthcare worker, your input could help with this research project.

The study aims to explore the experiences of healthcare workers with mesothelioma and develop recommendations for increasing awareness of the risk to healthcare workers. Researchers will interview a range of healthcare workers with mesothelioma including both clinical and non-clinical staff who work in hospitals. Mesothelioma UK is funding this study, alongside donations from the family and friends of the late Dr Mags Portman. It is being conducted by the Mesothelioma Patient Experience Research Group at the University of Sheffield.

The researchers are also analysing information gained from Freedom of Information requests sent to the NHS, regarding healthcare workers and mesothelioma. If you would like more information or can help with this study by taking part in an interview over the phone, please contact the team on 0788 581 7086.

# LIVING WELL WITH MESOTHELIOMA STUDY NOW CLOSED

The research study, Living Well with Mesothelioma, conducted by our Clinical Nurse Specialist, Karen Lord, is now closed to recruitment with 28 interviews having been carried out.

Karen and the research team would like to thank the patients, family members and staff who have discussed their experiences and given recommendations as to how to 'live well.' The first phase of the analysis is now taking place and results will be published in 2020.

# PROMISE-MESO TRIAL RESULTS

PROMISE-Meso is a key randomised phase III trial designed to test if pembrolizumab (an immunotherapy agent known as an anti-PD1 immune checkpoint inhibitor) was superior to single agent chemotherapy (vinorelbine or gemcitabine), usually used for patients with relapsed pleural mesothelioma.

The results of this trial were recently reported and presented by Professor Sanjay Popat, co-trial chair, at the European Society for Medical Oncology (ESMO) Congress 2019 in Barcelona, Spain. A total of 144 patients were recruited. Almost four times as many patients responded (good tumour shrinkage) to immunotherapy versus chemotherapy (22% versus 6%).

Unfortunately, these responses did not translate into a longer period without disease progression or death (i.e., the median progression-free survival was 2.5 months for pembrolizumab versus 3.4 months for chemotherapy) or improve survival (median 10.7 months for pembrolizumab versus 11.7 months for chemotherapy). Moreover, the PDL1 status of the tumour did not correlate with any benefit from pembrolizumab.

These findings are disappointing because immunotherapy had great hope for mesothelioma, but clearly demonstrate that in general, pembrolizumab does not improve outcomes over that seen with standard traditional chemotherapy. Professor Popat concluded that forging ahead, we need to do more research to find out those that might preferentially benefit more from pembrolizumab than chemotherapy, and also explore using immunotherapy in combination with chemotherapy by participating in one of several clinical trials currently open to newly-diagnosed patients.

Finally, he thanked all patients and carers for participating in the trial and moving forward scientific research.

# PATIENT STORIES

## FORMER RAF PILOT TALKS ABOUT LIVING WITH MESOTHELIOMA

John Myers, 74, was diagnosed with mesothelioma in November 2018. He is currently not on any medication, and is waiting to hear about treatment and trial options.

John, a former RAF pilot, lives in Poole with his wife and dog. He first noticed that something might be wrong when he began to get very breathless walking his dog in the hilly area around his home. John used to be able to do the daily walk with no problems.

An oncologist gave John the diagnosis of mesothelioma on 27 November.

Following his diagnosis, John was put in touch with HASAG, the asbestos disease support group covering the south and south east of England, London and the Home Counties. The team of Lynne, Lisa, Alison and Jo were "amazing" and introduced John to Mesothelioma UK's specialist armed forces mesothelioma nurse, Helen Wilkes.

John says that HASAG and Helen have been a tremendous support, helping him to complete all of the necessary paperwork relating to benefits, providing information and putting him in touch with the Veterans' Welfare Service.

Helen has been able to support John in a way that is relevant to him and his armed forces background. John says that Helen "understands the family affair of the forces and that's a big help".

For others who are diagnosed, John has this advice: "Basically they say 'you've got this disease, it is terminal, we can't cure it but we can manage it'.

"You just think 'Ah, wait a minute. That's it, that's the end'. But it isn't, you can go on, and people and organisations are there to help you do it. You are not alone.

"At the moment, I'm in the very early stages but I suppose as times goes on, things are going to get sticky and that's when I'm going to need the information to make my own decision about what I do next and that will be based on what Helen and other nurses tell me."

# THE INSPIRATIONAL CHRIS WILLIS

Chris is a 31-year-old PE teacher who told his story at our Patient and Carer Day in October 2019. Throughout his speech, Chris regularly thanked all the people in the room, especially the families and carers.

"My journey started in 2017, when I had started a new post at a new school and wanted to get fitter so started to cycle to work. After a few months, I started realising that I was losing some weight, but I put this down to more frequent exercise. However, more symptoms followed and eventually, I went to my GP as every meal I ate left me severely bloated.

"My GP suggested that my diet needed improving and I assumed my symptoms would clear up, however, they never did. (After several other treatments and developments) my 'lucky break' came in the form of Dr Cara Baker at St Thomas's Hospital, London, who offered to do exploratory surgery in early February 2018. The recovery was difficult, spending a full week in hospital. After the surgery, she told me she found over 10 small tumours in and around my abdomen.

"Thankfully, I got to meet my new CNS, the wonderful Rachel Thomas, who took me into a side room and never left my side. She talked through everything with me and got me fast-tracked into the consultation room to meet Professor Spicer, who was doing amazing things with the disease and the best man available to me at Guy's Hospital.

"I was told to go and enjoy my life and make some memories. And that's what we did all the way up to August 2018 when following (further) surgery after they suspected the mesothelioma was in my right lung now as well as my abdomen, the biopsy came back positive. It was then decided that chemotherapy was needed.

"My chemotherapy journey ended in February 2019 and all has been good since. We have been able to enjoy some 'normal' time. We wanted to make this time count, so Evelyn and I – along with friends – have done several charity events, including a half marathon and a coast-to-coast walk, raising over £6,000 for Mesothelioma UK, which we are really proud about.

"Living with mesothelioma can sometimes cause us to worry about the future, however one thing I have learned from surrounding myself with a lot of positive people is that nobody knows what the future holds for any of us. I was once told that's it's not how long you live for but how much of an impact your make while living that counts and I plan to live that philosophy to the best of my abilities.

"Currently, I feel fantastic and not on any treatment or medication at all. Evelyn and I are discussing family and trips every half term, starting with New York. I'm tirelessly trying to persuade Evelyn that I need a therapy dog!

"I've never been a person who gives myself much credit, but I am extremely proud of myself and what I have achieved. I battled through the hard times at the start and came back fighting. I am currently still working 50 hour weeks in my job, which I love, while trying to raise money and awareness for Mesothelioma UK to hopefully find that miracle drug we all want. I believe I have a lot more to give as a person and I won't let this disease defeat me. Only I can decide when enough it enough and it isn't yet. As my wife always says, 'we just never know what's around the corner and what will be will to be'."

You can read longer versions of these patient stories on our website at www.mesothelioma.uk.com/information-support/support/patient-family-experiences

# APPOINTMENTS

## NEW MESO UK SPECIALIST NURSE APPOINTED IN MANCHESTER

Lisa Clarke has been appointed as a Mesothelioma Clinical Nurse Specialist (CNS) to support patients across Manchester. Lisa will be based at Wythenshawe Hospital in Manchester, part of Manchester University NHS Foundation Trust. She previously worked as a Staff Nurse on the pulmonary oncology unit at the hospital.

Mesothelioma UK supports 25 Mesothelioma CNSs across the UK, each based within an NHS hospital and dedicated to providing expert, specialist mesothelioma support, information, treatment and care across the region in which they are based.

Before working at Wythenshawe Hospital, Lisa was a Staff Nurse for 11 years at the Salford Royal Hospital, working in neurosurgery. Lisa developed an interest in oncology through treating patients with spinal and brain tumours.

In her new role, Lisa will be offering both clinical help and practical advice such as where to go for benefits advice and support.

## WELCOME TO JULIE AND ALYSHIA

Julie (L) and Alyshia (R)

We're delighted to welcome two new members to our operational team. Julie Morton joins us as PA and Information Line Coordinator, and Alyshia Riley as Individual Giving Officer.

Julie will support the Head of Services and the Business Manager, as well as managing the information line while Alyshia will concentrate on supporting our fundraisers.

Julie joins Mesothelioma UK after working for the NHS in the community immunisation team where she gave administrative support to nurses for the school immunisation programme. Prior to that role, Julie was an administrator for the thoracic nursing team at Glenfield Hospital for 2.5 years. In this role, she had contact with both patient and healthcare staff and developed a keen interest in supporting people with thoracic diseases.

Alyshia has had varied roles in the past, from call centre manager to assistant producer at an independent film production company.

Alyshia's organisational and communication skills, and her passion for making a difference will ensure that our fundraisers receive all of the support that they need to do their challenges. Alyshia will also help to raise the profile of fundraising and support our annual campaigns such as Grow a Mo for Meso.

## NEW BENEFITS ADVISOR APPOINTED IN NEWCASTLE

Mesothelioma patients and carers in the North East can now access expert help and advice on welfare and compensation. Sarah Thomas has been appointed by Mesothelioma UK as a Mesothelioma Welfare Advisor, hosted by Newcastle Citizens Advice. She will cover the north east of England and this post has been made possible by the generosity of Mesothelioma UK supporters, particularly from the north east area.

The north east area has the highest rate of mesothelioma in the UK and there is an increasing need for more specialist welfare advice.

Sarah will be providing welfare advice to people affected by mesothelioma and their families. Sarah will advise clients through home visits, drop-in sessions, over the telephone and via email.

Patients will be able to receive help with claiming the welfare benefits and government lump sum compensation payments that they are eligible to receive.

Sarah has personal experience of mesothelioma in her family and will be working closely with Leah Taylor, the local Mesothelioma UK Clinical Nurse Specialist, and other specialist agencies and advisers to develop and expand the existing mesothelioma support available in the north east.

Sarah can be contacted at:
Citizens Advice Newcastle, 4th Floor, City Library,
Charles Avison Building, 33 New Bridge Street West,
Newcastle upon Tyne NE1 8AX
T: 0191 229 2750 ext 1260
M: 07741 659878
Sarah.Thomas@newcastlecab.org.uk
www.citizensadvice-newcastle.org.uk

# SUPPORTING OUR ARMED FORCES PROJECT

Mesothelioma UK's specialist service for Armed Forces personnel and veterans affected by mesothelioma is known as 'Mesothelioma UK - Supporting our Armed Forces'.

This service has been very well received by the Armed Forces community and the project continues to gather momentum, widening the range of contacts and links made.

- Mesothelioma UK Armed Forces Clinical Nurse Specialist and Benefits Advisor were recruited and work closely together on Armed Forces issues. Enquiries to the Mesothelioma UK information line are directed to them for support and advise
- A range of information leaflets have been developed aimed at raising awareness of asbestos exposure within the military in both the occupational and domestic settings

- A range of social media, including a dedicated Facebook group, are available to keep up to date on the project and case studies
- Awareness events proved to be a major factor in the growth of the project providing excellent networking opportunities and resulting in invitations to speak and exhibit at other events
- A new range of promotional materials have been developed including wristbands and badges
- A research project - Mesothelioma in the Military Experience Study (MiMES) has been developed in collaboration with the University of Sheffield and recruiting patients, carers and health care professionals
- A regular Mesothelioma UK Armed Forces email update is available for anyone interested in finding out more
- Mesothelioma UK is now a member of Veterans Gateway www.veteransgateway.org.uk and The Confederation of Service Charities (COBSEO) www.cobseo.org.uk

## MILITARY MESOTHELIOMA EXPERIENCE STUDY (MiMES)

Are you a family member of a veteran living with mesothelioma? Are you a health, legal or social professional who has experience of working with veterans living with mesothelioma? Are you interested in taking part in an interview? If so, we would appreciate your support and feedback.

Mesothelioma UK, in collaboration with the Mesothelioma Patient Experience Research Group at the Division of Nursing and Midwifery, University of Sheffield are looking for more patients, families and cares for the Military Mesothelioma Experience Study (MiMES). MiMES is being conducted as part of the wider 'Mesothelioma UK - Supporting our Armed Forces' initiative. MiMES aims 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 living with mesothelioma.

The team has made great progress conducting interviews with people with a diagnosis of mesothelioma, their family carers and relevant staff. We are grateful to all the people who have taken part in interviews as well as those who have helped with recruitment.

Please call our freephone information line on 0800 169 2409 to register your interest in participating in this study.

## ARMED FORCES CLINICAL NURSE SPECIALIST TAKES ON A FIRE WALKING CHALLENGE

Helen Wilkes, Mesothelioma UK Armed Forces Clinical Nurse Specialist took on a fire walking challenge to raise funds for Mesothelioma UK. Helen's brave efforts helped raise over £240. Well done Helen!

## NURSES LORRAINE AND MAIREAD VISIT BOROUGH OF BURY VETERANS' ASSOCIATION

Nurses Lorraine and Mairead visited Borough of Bury Veterans' Association to talk to its President, Chris Harness, and Welfare Officer, Marina Jones, about the 'Mesothelioma UK - Supporting Our Armed Forces' work. Great to be connecting with other organisations to offer support to veterans affected by mesothelioma.

# FUNDRAISING

## ARCA MEMBERS RAISE FUNDS TO SUPPORT MESOTHELIOMA UK

During this year's Charity Week, the Asbestos Removal Contractors Association staff and members got involved in various events and activities, raising over £5,500 for Mesothelioma UK.

Funds were raised by taking part in paintballing, a three-peak challenge, nuclear running events, hula hooping marathon, and there was lots of baking and eating.

Liz Darlison, Mesothelioma UK Head of Services, commented: "We are extremely grateful to everyone who took part in activities to raise funds for our charity again this year. This funding initiative provides a great opportunity for raising awareness, which is so important, and will help us to continue the work that we do in supporting people affected by mesothelioma across the UK."

## JAN'S RIDE ACROSS BRITAIN – OVER 21K RAISED TO FUND A MESOTHELIOMA NURSE FOR 1 YEAR

On 7 September 2019, Jan Mason took part in the Ride across Britain cycle ride in memory of her husband who died of mesothelioma. When Jan's husband, John was diagnosed, they were both shocked and frustrated by the lack of knowledge and information that was given to them about the disease and unfortunately, there was not a mesothelioma specialist nurse in their area at the time.

Specialist Lung Cancer Nurse, Hannah Ball, supported them from their point of diagnosis. Hannah was appointed as a Mesothelioma Clinical Nurse Specialist, funded by Mesothelioma UK, in 2015 and Jan began fundraising in that year to support Hannah's role, with the aim of raising enough money to support Hannah's post for a full year.

Jan began her initial training in January and being fairly new to road cycling, she quickly realised that it was going to be a tough ride! Her training comprised of three strength training sessions per week, plus three short bike rides of approximately 20 miles, and one long bike ride of 50 miles per week.

The challenge's distance totalled 980 miles and took nine days to complete - an estimate of 110 miles per day, every day for nine days, whatever the weather. It took Jan around 10-12 hours of gruelling bike riding every day followed by sleeping in a tent. In total, she climbed 52,000ft, including pedalling up Cheddar Gorge, Shap Fell and Glenshee.

Jan rose to the challenge and raised a total of over £21,000 which Meso UK put towards funding a Mesothelioma Clinical Nurse Specialist.

# CHANISE KEMP CLIMBS LONDON O2 BUILDING

"Our dad was diagnosed on 6 September 2017 with peritoneal mesothelioma and sadly lost his battle on the 27 September 2017.

"Since losing dad we have tried to raise awareness and money for Mesothelioma UK. As a family, the help and support that we received during such a traumatic and emotional time was invaluable.

"Mum and Dad were soulmates from their early teens and were married for over 30 years. They spent almost 40 years together, during which time they were blessed with four children and now 10 - soon to be 11 - grandchildren.

"Dad had a wicked sense of humour and was the traditional good samaritan helping anybody out, whenever possible. Dad's passion was riding his motorcycle when our Cornish weather allowed it! His personality and his heart were huge, and he is greatly missed by everyone whose lives he touched.

"Since our loss we have so far managed to raise almost £1,700 in a variety of ways to honour his name. For the latest fundraising, I thought it would be a good idea to climb the London 02 which has raised almost £800.

"We will continue to raise money and awareness whenever possible, and wish everyone luck in their own battle against this dreadful disease."

# SADIE DOUGAN'S SNOWDON CLIMB

Sadie climbed Snowdon to raise money for Mesothelioma UK as her Grandad died in 2017. Sadie has tirelessly raised money for Mesothelioma UK who provided the family with help and advice when they needed it most.

The route was 5.5km each way and no easy feat for a 10-year-old, plus she camped out for two nights and managed to raise an incredible £1,084.52!

# CAROL PROBERT'S COFFEE MORNING

"On 8 June this year, we had a coffee morning in aid of Mesothelioma UK, in memory of my late husband David Probert who succumbed to mesothelioma in December 2018. It was something that I had promised myself I would do when he was diagnosed earlier that year.

"Unfortunately, the weather was not favourable so the house was crowded for a few hours, but this all added to the entertainment! As well as tea, coffee and a multitude of delicious cakes made by me, neighbours and friends, we also held a very well supported raffle.

"Anna, the eldest daughter of Dave's best friend Tim, did an impromptu auction of a splendid strawberry cheesecake and two cream sponges, which increased the total raised by £40. We also sold Mesothelioma UK pin badges, trolley tokens and wristbands.

"Thank you so much to all who attended and were so generous. We raised the magnificent sum of £1,225.50 for a very deserving cause. A huge thank you to my neighbours and friends who helped on the day; they were instrumental in raising the amount that we did.

"We all need true friends in difficult times and in this respect, I have been very lucky."

# RAVI, MEERA AND AMI CLIMB KILIMANJARO IN MEMORY OF THEIR FATHER AND UNCLE

Arvind Ruparelia touched hearts wherever he went and was a friendly, and a very loved member of the family and community. He committed a lot of time to the local temple and lived to make a difference.

Sadly, Ravi and Meera's dad passed away on 22 September 2016 following a courageous fight against mesothelioma. To have had a couple of extra months with their dad would have been priceless to them and the family. Mesothelioma UK provided them with further information during this tough time, including researching clinical trials, which is why they decided to raise funds for the charity.

Ravi tries to channel his dad's thoughts and energy into everything he does and nearly one year after successfully donating his kidney to his cousin, he, alongside his sister Meera and cousin Ami, chose to climb Mount Kilimanjaro on 19 August 2019. The trio completed their challenge climbing Kilimanjaro, as well as climbing Snowdon and Ben Nevis some weeks before and in total, raised an astonishing £13,009.61 in support of Mesothelioma UK. They look forward to raising more money in the coming months.

# ROCK N ROAST BY SALLY COLLINS RAISES AMAZING £9,359

Sally's journey started in May 2018 after she believed that she had injured her back whilst gardening. Upon visiting her doctor, she was referred for a scan and the result showed fluid in her chest cavity. Unfortunately, although her case was atypical, on 4 October, it was confirmed that Sally had mesothelioma at the age of 48.

Whilst Sally was going through tests, a shadow showed up on her right breast and it transpired that she also has breast cancer. Having received amazing treatment from the NHS to date, she decided to give something back. Firstly, Sally had her long hair cut on 20 December and donated it to the Little Princesses' charity which donates wigs free of charge to children suffering from hair loss as a result of cancer treatment.

Sally also asked her friends to donate to either Mesothelioma UK or Breast Cancer UK. Sally set up a Just Giving page, and she organised and ran a Rock n Roast event which raised an outstanding £9,359! Along with amounts raised by her friends, family and supporters, she raised a grand total of £12,844.19.

# J ENGLAND ENVIRONMENTAL SERVICES

As part of the ARCA Charity Week, members from J England Environmental Services took part in the Nuclear Races Mud Run as well as holding an office bake sale raising over £1,000.

# TIM STOKES, SUNDAY CLUB ROAD TRIP

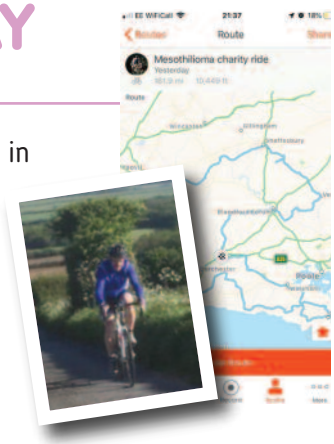
Tim Stokes' 80 Mile Cycle Ride with his son Ollie and friends.

"Whist trying to come to terms with my prognosis/ mortality and trying to explain it to my kids, I've been reading a little philosophy and I've noticed one key thing: 'we all seek happiness, feeling that winning the lottery, a promotion at work, a new convertible car, making love, will make us happy! But these are illusions as much as alcohol and drugs, they are pleasant, but transient feelings. And the more we have, the more we desire. Real happiness comes from spending time with friends, helping others, acts of human kindness. This is where inner peace lies.'

"I'm only cycling for about 80 miles over a weekend; I'm just spending precious time with my friends! But I have just one working lung. I've lived about 1,300 days longer than they said I would, I've tried all available chemotherapy and immunotherapy, and I'm still terminal. Mesothelioma is the biggest fatal industrial disease killing children, teachers, servicemen, anyone accidentally exposed to asbestos. Massive gains have been made in the past few years and people are starting to survive this cancer much longer."

Tim, Ollie and his friends raised a wonderful £1,785.62.

# PAUL GAMBLE 160 MILE RIDE IN 1 DAY




Paul Gamble cycled 160 miles in one day to raise money and awareness for Mesothelioma UK as his father-in-law was recently diagnosed with mesothelioma. He raised an incredible £1,116.25.

# NAVAEH WATERS RAISES £276.25 IN MEMORY OF HER GRANDADS

"One day I was very sad and thinking about how much I miss both my grandads and because I couldn't do anything about it, I thought that I should help other people instead. So, I decided to grow my hair long and then donate it to children who need wigs.

"My Grandad Ron will always hold a special place in my heart. Me and my mum were lucky enough to live with him and my nan for three years and I have so many memories with him, like playing horsey, eating his cornflakes over his shoulder, cups of tea in bed and just cuddling up and watching Garfield. I miss him every day and love him so much.

"My Grandad Peter was such a funny man. He would always mess around with my nanny June and play little pranks on her. They were together for over 60 years and they loved each other so much. We went out on boat trips together and he was always giving me Kit Kats when I came around.

"I am very lucky to have had two very loving grandads in my life. I was very nervous getting my hair cut but once I had it done, I really loved it and I want to keep it this short now as everyone has said how lovely it looks. My family are super proud of me and they helped me raise so much money."

# JAKOB AND CHARLOTTE'S RUN IN MEMORY OF THEIR FATHER

Jakob Thornton lost his father, Graham, to mesothelioma in 2016. After Graham was diagnosed in May 2014, he lived his life to the fullest and bravely right up until his death in October 2016.

Jakob and his sister Charlotte took part in the New Forest Half-Marathon together in memory of their Dad for Mesothelioma UK and raised an incredible £1,422.50! Amazing work and a fantastic contribution to the charity.

# SALLY'S ANNUAL SUMMER EVENT RAISES £500 FOR MESO UK

"On Wednesday 21 August, my family and I held our 7th annual summer event to raise funds for those affected by mesothelioma, in memory of my husband, Michael Reedman. My four granddaughters all played their part during the day and wore their t-shirts with pride as you can see in the photograph. We managed to raise a grand total of £1,675 that was divided between Asbestos Support Central England and Mesothelioma UK."

# ADRIAN'S "IN MEMORY OF MUM" CYCLE RIDE

"On 9 July 2018, my mum, Pauline passed away after battling mesothelioma. Mum grew up in Newport, Wales and on Saturday 6 July 2019, I cycled from her home on Enville Road to Haddenham in Buckinghamshire, our family home for over 30 years. The journey was 120 miles and took 11 hours to complete. In total I managed to raise almost £1,600 for Mesothelioma UK."

# JURASSIC COAST CHALLENGE IN MEMORY OF JANICE ALLEN

Stuart Allen, along with Louise, Matthew, Katie, and Jessie, decided to take on the hilliest section of the Jurassic coast on 8 June to support Mesothelioma UK. It marked one year to the day since they lost their beloved wife/mother/mother-in-law/sister and friend, Janice Allen. They raised an amazing £2,478.56.

# JESSICA BATHGATE RAISES £1,035 IN MESO UK & MAV CHARITY NIGHT

# LINDSAY FORD SWANSEA TRIATHLON AND MORE

Lindsay Ford's dad is currently fighting mesothelioma, so in support of him and Mesothelioma UK, Lindsay has been taking part in different challenges to raise money. She recently took part in the Swansea Triathlon and raised £300.00.

# SAMANTHA SHAW'S 2 GREAT SWIMS IN 2 WEEKS

"My challenge was completing two of the Great Swims in two weeks. I swam the 10km (longest distance) in Lake Windermere as part of the Great North Swim on 9 June. This was particularly challenging as the weather had been really bad leading up to the event, meaning that the water temperature dropped to 13 degrees. It was also very windy, causing the water to be choppy! After three hours of continuous swimming, I successfully completed the course.

"Two weeks later, on 22 June, I completed the 10km swim at Alton Water as part of the Great East Swim. This time it was a much warmer 19 degrees so felt like a bath compared to Windermere! I again completed the swim in three hours. It was a big personal challenge, but I was very proud to raise a total of £473.00 and to raise awareness for Mesothelioma UK."

# ROBERT'S SKYDIVE

Robert Mullins' brother-in-law, Ray, was diagnosed with mesothelioma. Robert took part in a sponsored sky-dive and raised £496.75 for Mesothelioma UK.

# ELINA'S 5KM FUN RUN!

Elina Cole completed the 5K colour obstacle run in Wolverhampton on 27 July 2019 as she lost both of her grandads to mesothelioma. Elina and three of her friends tackled the challenge, each choosing their own charity to support. Elina kindly chose Mesothelioma UK, raising a fantastic £220.00.

# PAUL HOLLOWAY AND NATASHA ALDOUS WEDDING

"In June this year, you sent my fiancée, Natasha Aldous, some badges for us to pass out as wedding favours (alongside our donation). Our big day took place on Saturday 12 October. Whilst my father (Malcolm) knew Natasha well, he died years before we started talking about marriage. I am certain that he would have been very happy to know of the news and would have loved to share our day with us. I take some comfort in knowing that he's looking down on us both. We hope that he's proud.

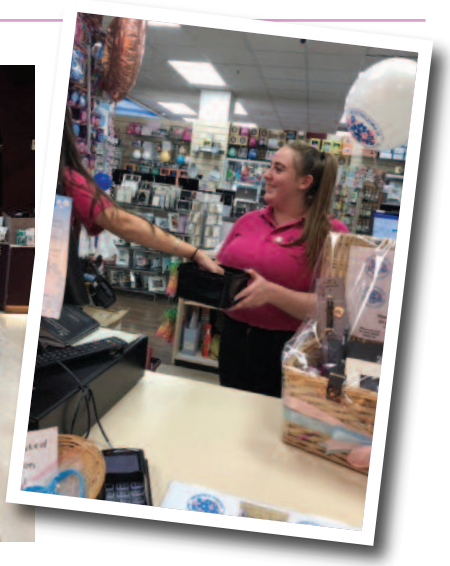
"Thank you for the work that you all do. Your work and the trial treatments that my father received gave us all hope when we needed it the most."

Paul Holloway & Natasha Aldous (now Natasha Aldous-Holloway)

## THE VITALITY BIG HALF IN SUPPORT OF CHRIS WILLIS

Alexandra Robin's good friend, Chris Willis was diagnosed with mesothelioma last year. Chris has been battling through the illness and working incredibly hard to live as normal a life as possible. Alexandra ran/walked the 'The Vitality Big Half Marathon' alongside Chris and his wife, and raised £57.50 in support of Chris and Mesothelioma UK.

## CASEY'S RAFFLE FOR MESO UK



Casey McCleave held a raffle in September 2019 in support of her grandad Richard and raised a fantastic £215.37!

# IRWIN MITCHELL CHARITY QUIZ NIGHT

Over £3,000 was raised for Mesothelioma UK in September by the dedicated asbestos team at Irwin Mitchell Solicitors and their supporters at their offices in Holborn.

The now annual event, hosted by the London team at Irwin Mitchell, was a wonderful celebration of the incredible work that Mesothelioma UK does to support victims and their families facing mesothelioma.

The quiz night was relaxed and fun, with over 80 guests vying for the coveted top prize. With participants from the world of law, medicine and accountancy, the competition was always going to be strong.

Moving speeches by former Irwin Mitchell clients Mick May and Ravi Ruparelia highlighted just how important the work of Mesothelioma UK is to victims and their families, the amazing support that is provided by the charity and the direct impact that every fundraising pound can make. All guests dug deep into their pockets to buy raffle tickets, drinks and make donations.

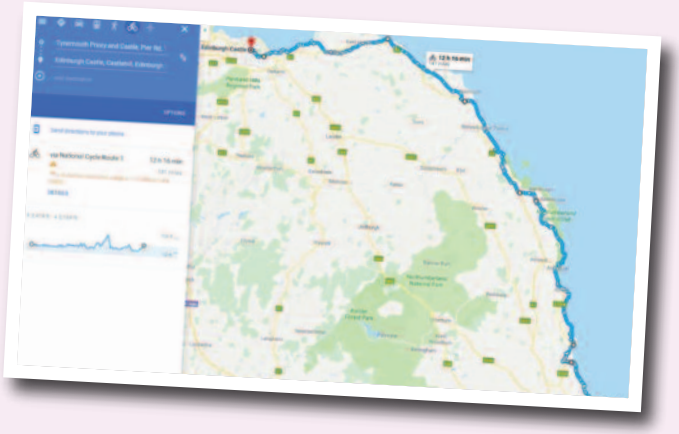
Chief organiser of the event, Lacey St James from Irwin Mitchell said: "We are so proud to support asbestos victims and to raise an amazing £3,000 for Mesothelioma UK. The quiz night has become a favourite annual event and this year was bigger than ever."

Leading oncologist from Bart's Hospital, Professor Jeremy Steele, gave everybody some insight into the broad geographical range of Mesothelioma UK and the plans to expand to provide even more support for sufferers.

The event was supported by generous local businesses, barristers and litigation experts who donated prizes for the charity with the top prize of a helicopter ride for two people.

# STEVEN BURNS COASTS & CASTLES

On 12 July 2019, Steven Burns completed a personal challenge to raise awareness for Mesothelioma UK - Coasts & Castles in one day. Travelling from Tynemouth Priory and Castle up to Edinburgh Castle by bike, Steven raised an incredible £490.06.



# RON ON THE RUN

64-year-old Ron Snaith trained for his 39th consecutive Great North Run this year, despite having being diagnosed with mesothelioma in late 2018. He managed to complete it with the help of his family (part walking/part wheelchair), only one week after having chemotherapy. He raised £1,345 and his daughter-in-law has raised another £1,000 from a Charity Fun Day.

Mesothelioma UK exists to raise funds to support the services that we provide 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 donor, please contact us on 0800 169 2409 or email info@mesothelioma.uk.com

## Events Calendar

**London Winter Walk**
**19 January 2020**
London
www.mesothelioma.uk.com/getting-involved/fundraising

**Fitness February**
**Throughout February**
www.mesothelioma.uk.com/getting-involved/fundraising

**Mesothelioma UK Ladies' Lunch**
**6 March 2020**
Manchester
www.mesothelioma.uk.com/news-events/events-calendar

**Easter 50 Challenge, Windsor**
**11 April 2020**
Run, walk or jog 50 or 25km
www.ultrachallenge.com/easter-challenge

**Isle of Wight Challenge**
**2-3 May 2020**
106km full island challenge with half and quarter distance options
www.ultrachallenge.com/isle-of-wight-challenge

**Jurassic Coast Challenge**
**16-17 May 2020**
100km challenge with half and quarter distance options
www.ultrachallenge.com/jurassic-coast-challenge

**Patient and Carer Day**
**2 October 2020**
The Harbour Hotel, Southampton
www.mesothelioma.uk.com/news-events/events-calendar

Please send details of any local events to meso@sandstarcomms.com so that they can be added to the Meso UK website.

## Gold Donors 2019/20

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