MESOTHELIOMA MATTERS

Spring 2019

CLASAG launches for Cumbria and Lancashire patients

Mesothelioma Research Programme
LEICESTER

MiST trial opens for recruitment

New Meso UK nurse in Scotland

2019 events for your diary

MESOTHELIOMA UK
Supporting People With This Asbestos Cancer

LAUNCH OF NEW ADVICE CENTRE FOR BARROW ASBESTOS VICTIMS

A critical support group for people with asbestos conditions was under threat of closure, but thanks to Blackpool-based charity Disability First, the support group has been rescued and given a new title, CLASAG - Cumbria & Lancashire Asbestos Support Advice Group.

Formally known as CARDS, Cumbria Asbestos Related Disease Support and chaired by Bob Pointer, the support group was an organisation based in Barrow-in-Furness, established in 2006. It was dedicated to giving help; information and support to anyone affected by asbestos-related diseases living in Cumbria and North Lancashire, and was a very active group under Bob's leadership.

Rachel Minshull, Barrow & Furness Development Officer for Cancer Care said: "I have worked with Bob and CARDS for the last two years and have seen many people helped during that time. Bob's commitment to CARDS and other asbestos-related issues has been an eye opener for me. Not many would have continued doing so much on their own but he did and he did a good job of it. I wish Bob all the best in his retirement. I have no doubt that Disability First will put just as much effort, energy and enthusiasm into CLASAG, and I look forward to continuing to work with the group."

Bob said: "Since our launch on the first Action Mesothelioma Day 2006, we have experienced setbacks, obstacles and time constraints, but we survived and I am really happy to hand the reins over to Disability First to ensure that the group thrives and expands its network of support."

"We are thrilled and very proud to be asked by Bob and the group to continue all the hard work that has been achieved and wish Bob all the very best in his retirement," says Alan Reid, the CEO. "As well as the support group meetings, patients will be able to get independent advice about welfare benefits and compensation through the home visiting service."

Graham Dring, Chair of the Asbestos Victims Support Groups Forum UK said: "It is great news that CLASAG will be continuing the excellent work of CARDS. Barrow has been deeply affected by asbestos-related diseases because of the widespread use of asbestos in the shipbuilding industry. It is crucial that local people have access to independent, expert advice on benefits and compensation, and ongoing support so the establishment of CLASAG is welcome news for victims of asbestos diseases and their families. I would also like to take the opportunity to thank Bob Pointer who has been involved with CARDS since its inception and has run the organisation almost single-handed for the last few years."

The Asbestos Victims Support Groups Forum UK is a national body that represents 13 independent asbestos victims support groups in England, Scotland and Wales.

Lorraine Creech, Mesothelioma UK Clinical Nurse Specialist and Team Leader added: "We're delighted to welcome the new CLASAG body to the UK network of support groups for mesothelioma patients, their carers and their families. We look forward to working with the CLASAG team to extend support for the mesothelioma community in and around Cumbria, Barrow and Lancashire."

Meetings will be held on the third Monday of each month at the Barrow & District Disability Association, School Street, Barrow LA14 1EJ.

For more information, contact Alan Reid 07541 222 852 or email alanreid@disabilityfirst.org

NATIONAL MESOTHELIOMA AUDIT

In January 2019, the National Mesothelioma Audit (NMA), hosted by the Royal College of Physicians, began its mesothelioma organisational audit. The purpose of this audit is to identify mesothelioma specific multidisciplinary teams (MDTs) across the whole of the UK and provide an evidence-based definition for these MDTs.

Phase 1 of this project concluded in mid-February as sites across England, Wales, Scotland and Northern Ireland completed a short online survey. This survey was designed to help the NMA team and Mesothelioma UK identify where mesothelioma specific MDTs are based. Clinical teams were asked questions about diagnosis and referral of mesothelioma patients.

Dr Susan Harden

For phase 2, Susie Harden, clinical oncologist and co-clinical lead for the NMA, will be contacting these MDTs to better understand how they work and the resources and facilities available to them for diagnosing and treating their mesothelioma patients. We expect there to be over 15 of these MDTs in total.

Initial results will be presented at the (BTOG and Mesothelioma UK) Mesothelioma Essential Update 2019 on 11 March. Later in 2019, we will have a summary report and a directory of these MDTs available on the Mesothelioma UK website.

The next NMA report, covering 2016-18 data, will be published in spring 2020.

Mesothelioma UK would like to acknowledge Pat Stone Mesothelioma Support who provided funding to enable this audit to be completed.

NEW RESEARCH INTO IMMUNOLOGY AND MESOTHELIOMA

Scientists at King's College London will test a new technique that could directly target an aggressive form of cancer.

Funded by Mesothelioma UK and awarded through the British Lung Foundation Research Grants, Dr John Maher and a team of researchers will programme white blood cells to recognise specific proteins that are present at higher levels on mesothelioma tumour cells, compared to normal cells. This research aims to teach the white blood cells, which are part of the body's normal mechanism of fighting infection, to recognise mesothelioma and shut down the processes that enable tumours to grow and spread around the body.

Dr John Maher, Honorary Consultant in Immunology at King's College London and Consultant in Immunology at Eastbourne Hospital, said: "Although treatments already exist to slow down the progress of tumour growth and development in patients with mesothelioma, these treatments often fail and can also attack healthy cells and cause unpleasant side effects, such as vomiting, diarrhoea and fatigue.

"By reprogramming immune white blood cells to recognise tumours and attack them directly, immunotherapy offers the possibility of targeted treatment which could significantly improve outcomes for people diagnosed with mesothelioma."

Ian Jarrold, Head of Research at the British Lung Foundation, added: "Being diagnosed with mesothelioma is a devastating experience that far too many people go through every year. Investing in cutting-edge research is critical to understanding how this terrible disease operates and we believe that immunotherapy has huge potential to transform the lives of those living with mesothelioma in the UK."

Liz Darlison, Head of Services at Mesothelioma UK, added: "Mesothelioma has claimed far too many lives in the UK and new treatments are urgently needed for people affected by this cruel disease.

"Evidence on the efficacy of immunotherapy, as well as new treatments that offer the possibility of better outcomes, is essential for people living with mesothelioma in the UK. Mesothelioma UK is committed to funding research and we sincerely wish Dr Maher and his team well with this study."

JDR CABLE SYSTEMS LTD SELECTS MESO UK AS 2019 CHARITY

Christian Wain and Mandy Marriner from JDR Cable Systems at the company's 2018 Charity Summer Ball

JDR Cable Systems Ltd, a global expert in subsea cables and umbilicals, provides the vital connection to both the renewable energy and oil & gas industry. The company has announced that its chosen charity for 2019 will be Mesothelioma UK, along with local support group PRASAG (Paul Readhead Asbestos Support Awareness Group).

As part of JDR's commitment to supporting its community, JDR organises events year-on-year to raise money in support of its respective local charities. This year's support for Mesothelioma UK will help to raise awareness of mesothelioma, supporting local specialist nursing units, and help local support groups that give the patients and their families a lifeline through counselling and guidance.

JDR welcomes everyone to join it for any of its fundraising events during 2019, especially the 7th Annual Charity Summer Ball 'The Grand Prix Dinner' which will be held on Friday 26 July 2019 at Hardwick Hall Hotel, Sedgefield, County Durham. Tickets are now available and can be purchased online via the website www.jdrcharityevents.co.uk.

Further fundraising events for Mesothelioma UK & PRASAG during 2019 include:

- Friday 19 April 2019: Team Karting Endurance Race at the Teesside Karting Autodrome with prize giving by F1 Race Engineering celebrity, Rob Smedley
- July 2019 date TBC: 2-day sponsored Coast and Castles 200 mile Edinburgh to Newcastle Cycling Challenge
- 26 July 2019: 7th Annual Charity Summer Ball, Hardwick Hall Hotel, Sedgefield
- Summer 2019 date TBC: Charity Golf Day, location TBC
- Late August 2019: Sponsored Hadrian's Wall Family Walk, with overnight camping stop and barbeque

Christian Wain, Senior Production Engineer at JDR, said: "We are thrilled to have announced that JDR will be supporting fundraising for Mesothelioma UK and PRASAG throughout 2019. It is so important that we raise a greater awareness and understanding of mesothelioma. JDR's voice throughout the industry will help spread the message far and wide that action needs to be taken. It's so exciting to see five fundraising events already planned for 2019 including our 7th Annual Charity Summer Ball on Friday 26 July where everyone is most welcome."

Liz Darlison, Head of Services at Mesothelioma UK, added: "We're delighted that JDR Cable Systems Ltd has chosen Mesothelioma UK and PRASAG, our local support group in the north east, as their chosen charity for 2019. "Their support means so much to all of us and most importantly to our patients. We wish them every success in their calendar of fundraising events in 2019."

TRAY BAKED CHICKEN AND TOMATOES (SERVES 4)

This is a simple, delicious one pot dish – great if you're feeling tired and don't have energy to chop and prepare food. If you are struggling with taste changes, the chilli and tomatoes may help give your tastebuds a kick. If you are struggling with spicy foods, just leave the chilli out.

Ingredients

4 chicken quarters
Salt
Pepper
1 big bunch of basil, leaves picked and stalks finely chopped
2 large handfuls of cherry tomatoes, halved (can use red and yellow or plum tomatoes for variety)
1 whole bulb garlic, broken into cloves
1 fresh red chilli, finely chopped
Olive oil
1 large tin cannellini beans
2 handfuls new potatoes, scrubbed and halved

Method

1. Preheat your oven to 180°C/350°F/gas 4. Season your chicken quarters with salt and pepper and put them into a snug-fitting pan in one layer. Add the basil leaves and stalks, tomatoes, garlic cloves, chopped chilli, potatoes and cannellini beans and drizzle over some olive oil. Mix around a bit and push underneath the chicken quarters. Place in the oven for 1½ hours until the chicken skin is crisp and the meat falls off the bone.

2. Serve.

As an alternative, you could leave out the new potatoes and serve with mashed potatoes or shred the chicken off the bone and mix with a bowl of linguini or spaghetti.

COLLABORATIVE PROJECT FOR PERITONEAL MESOTHELIOMA

By Sarah Ennis, Professor of Genomics at University of Southampton

Peritoneal cancer is a rare cancer that can develop from within a thin layer of tissue that lines the abdomen. This lining is called the peritoneum and is made of epithelial cells that produce fluid to help organs move smoothly inside the abdomen.

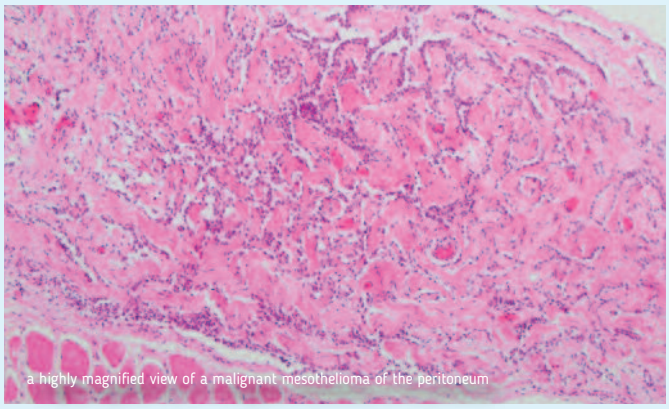
Mesothelioma of the peritoneum is rare. However, the malignant subtypes of peritoneal mesothelioma are highly aggressive and progress rapidly in the absence of invasive treatment, but there are also low-grade subtypes that are generally amenable to treatment using local therapy. There is a pressing need to identify genetic signatures that distinguish aggressive from non-aggressive subtypes and so help clinicians target radical treatment to those patients that will benefit. In other cancers, this approach to improving understanding of individual tumour genetic profiles has led to the development of new therapies that directly target the molecular changes specific to the tumour.

Mesothelioma UK has recently approved funding for a collaborative project between the University of Southampton Genomic Informatics Group, a world recognised expert in cellular pathology with specific expertise in peritoneal malignancy and the Peritoneal Malignancy Institute (PMI), Basingstoke, which is one of the highest volume centres in the world for peritoneal malignancy. This project aims to characterise peritoneal cancers, with a focus on peritoneal mesotheliomas, to catalogue the key transformative genetic changes driving these tumours.

Tumour samples that have been collected and stored by the Peritoneal Malignancy Institute at Basingstoke will be selected for cutting-edge genetic analyses.

Peritoneal tumours can be tricky to analyse as the tumours produce large amounts of mucous and this can make it difficult to extract good quality DNA for analysis. The project aims to choose almost 400 samples with the best quality DNA and screen each of these samples to identify mutations that transformed the cells to become cancerous. About 2,800 cancer mutation hotspots across 50 of the most important known cancer genes will be screened in every tumour sample. This generates a lot of data that will be analysed by the Genomic Informatics Group at the University of Southampton. Advising on the analysis will be Norman Carr who is a world-renowned expert on these rare peritoneal cancers.

The ultimate aim of the project is to better understand the exact changes that can occur in these tumours and determine which mutations lead to rapidly progressing aggressive disease. This could mean that in the future, when new patients are diagnosed, clinicians are better able to predict the likely behaviour of the tumours and select the most appropriate treatment. The goal is always to improve the information available to provide the best possible patient care.



a highly magnified view of a malignant mesothelioma of the peritoneum

TRAVEL GRANTS FOR MESO PATIENTS

Mesothelioma UK acknowledges that people diagnosed with mesothelioma do not always have access to specialist care at their local hospitals. Therefore, we offer grants to support travel expenses for those attending specialist centres to access a clinical trial. This helps to ensure that everyone has equal access to specialists, treatment, trials and care, regardless of where they live.

Since 1 April 2018, we have supported 49 patients with travel expenses for appointments, totalling **£34,831.66**.

If you are having to travel to clinical trials, you may be eligible for a grant. Claim forms are available from Mesothelioma UK by calling 0800 169 2409 or emailing info@mesothelioma.uk.com

WOMEN, MEN AND GENDERED EXPERIENCES OF MESOTHELIOMA

The incidence of mesothelioma is higher in certain occupational groups including asbestos mining and disposal and construction industries (Rake et al 2009). These are industries and occupations that have traditionally had higher rates of male employment. There is a lack of knowledge and understanding of the occupational and environmental exposure of women to asbestos and related mesothelioma diagnosis.

There are new treatments for mesothelioma that offer promise in terms of length and quality of life. It is important to explore any factors influencing access and uptake to new treatments to avoid potential inequalities, including those based on gender.

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. Initial consultation suggests that women are:

- Less likely to be aware of their exposure and risk
- Less likely to have clear occupational link
- Be less likely to be diagnosed quickly and at an early stage
- Encounter assumptions that women are exposed through para-occupation e.g. from work clothes of male family member rather than their own occupation or environmental exposure
- Less likely to have a claim for benefits or compensation processed

On International Women's Day, 8 March 2019, Mesothelioma UK held a 'Ladies' Lunch' that was centred around the Gendered Experiences of Mesothelioma (GEM) study. The proposed study will explore men and women's experiences of mesothelioma to identify the implications for health, social care and legal practices.

We aim to start the project in spring 2019. Later in the year we will be recruiting people to interview them about their mesothelioma experiences. The interviews will be conducted by phone.

If you are interested in knowing more about the study – or in taking part – more information will be available from Mesothelioma UK by emailing info@mesothelioma.uk.com or calling 0800 169 2409.

Thanks to HASAG, Irwin Mitchell, Papworth Mesothelioma Social and Royds Withy King who have provided funding for this valuable study.

MESOTHELIOMA SPECIALIST NURSE APPOINTED IN SCOTLAND

Carolyn MacRae has been appointed as Mesothelioma Clinical Nurse Specialist (CNS) in Scotland. Carolyn returns to this role following maternity leave. During this time, Carolyn's role was covered by Laura McNaughton. Carolyn will be responsible for supporting mesothelioma patients undergoing treatment at Greater Glasgow and Clyde NHS Trust, and will be based at Queen Elizabeth Hospital in Glasgow.

Carolyn will support the national mesothelioma clinical helpline, advise on clinical trials, and provide palliative and end of life care and support.

After qualifying in 2000, Carolyn worked on respiratory wards and became a Clinical Nurse Specialist in 2007. For over 10 years she has worked in the acute, community, educational and outpatient setting predominantly with patients with chronic obstructive pulmonary disease (COPD) and interstitial lung disease at Queen Elizabeth University Hospital.

Commenting on her new role, Carolyn said: "I feel very privileged to be working as a Mesothelioma CNS in collaboration and with support from Mesothelioma UK. In Scotland, we are part of a dynamic team dedicated to providing patients with the care, information and support they need and deserve."

Liz Darlison, Mesothelioma UK Head of Services, added: "We have an amazing team of Clinical Nurse Specialists across England, Scotland and Wales, and are committed to growing this team even further to manage the increasing incidences of this deadly disease in the UK. Carolyn's appointment will give us a centralised contact for patients in Scotland."

MESOTRAP CLINICAL TRIAL UPDATE

MesoTRAP is a pilot clinical trial and feasibility study looking at symptom management for patients with trapped lung to determine the best treatment for patients with mesothelioma and pleural effusion.

It compares video-assisted surgery (thoracoscopic partial pleurectomy/decortication) with indwelling pleural catheter (IPC) in patients with trapped lung. There is also an observational only sub-study which collects routine data only on patients who are not eligible for the main study.

The study requires more participants and is extending the recruitment to December 2019 to gather as much data as possible.

Healthcare professionals are encouraged to inform any patient with trapped lung about the observational study if they are not eligible for the main study.

Centres open to recruitment are Blackpool, Cambridge, Derby, Golden Jubilee Glasgow, Leicester, Norfolk and Norwich, North Bristol, North Midlands, Nottingham, Oxford, Papworth, Peterborough, Preston, Sheffield, St Bartholemew's London, Wythenshawe and Pennine.

Trial details are in the enclosed clinical trials table and further information is available by emailing papworth.mesotraptrial@nhs.net

Contact Mesothelioma UK:

Freephone

0800 169 2409

info@mesothelioma.uk.com

www.mesothelioma.uk.com

FROM ANTI-COLD TO ANTI-CANCER

By Bethan G. Rogoyski and Karen Brown, Leicester Cancer Research Centre, University of Leicester

In the mid-eighties, mounting scientific evidence led to a national embargo on the use of asbestos. Since then, thousands of workers who were exposed to asbestos have been left living under the shadow of a looming diagnosis, their risk of developing mesothelioma dozens of times higher than it could have been. The 50-year latency period between exposure and diagnosis often amounts to a lifetime of living in limbo for those occupationally exposed to asbestos.

However, this time lag between asbestos exposure and mesothelioma diagnosis, combined with the knowledge that there are specific populations at high-risk, provides an opportunity for the development and use of preventive therapies. Therefore, four years ago, we began testing a panel of old established drugs for their potential to delay or prevent the growth of mesothelioma.

This panel included 100 off-patent drugs which have been widely used for the treatment or management of a range of conditions, including everything from high blood pressure, antibiotics and vitamin supplements. This idea of repurposing old drugs for new uses is particularly valuable when searching for preventive therapies.

This is because we need drugs that are safe and well-tolerated, as the groups of people we aim to use them with do not yet have cancer, and indeed the majority will never develop cancer, so it is not acceptable to give them drugs with harmful side effects.

Other major advantages of drug repurposing are that it takes around half the time and is a quarter of the cost of developing new drugs from scratch.

Beginning by testing these drugs on mesothelioma cells in the laboratory, we identified those that consistently reduced cell growth and caused cell death. We selected the most potent drugs with favourable safety profiles to test further in patient tumour tissue cultured in the laboratory and mouse models of mesothelioma for their ability to inhibit tumour growth.

The top two drugs, one primarily used as an anti-worming tablet, the other a common component in cold lozenges, were both studied at the same doses they are already safely prescribed at for other diseases, meaning their use against mesothelioma could be expedited.

Our work is still in the early stages, but next we need to test the best drugs in short-term clinical trials to investigate whether the biological effects we observe in the laboratory translate to patients, before conducting larger prevention trials in people at high-risk of developing mesothelioma.

Additionally, there is scope for screening hundreds of other established drugs to identify more candidate therapies that might be effective for reducing cancer cell growth, and subsequently preventing mesothelioma in high-risk populations, before it becomes a full-blown and deadly cancer. This would circumvent patients having to experience both the disease itself and the need for them to undergo more gruelling traditional chemotherapy regimens.

This project is funded by a Cancer Research UK PhD studentship.

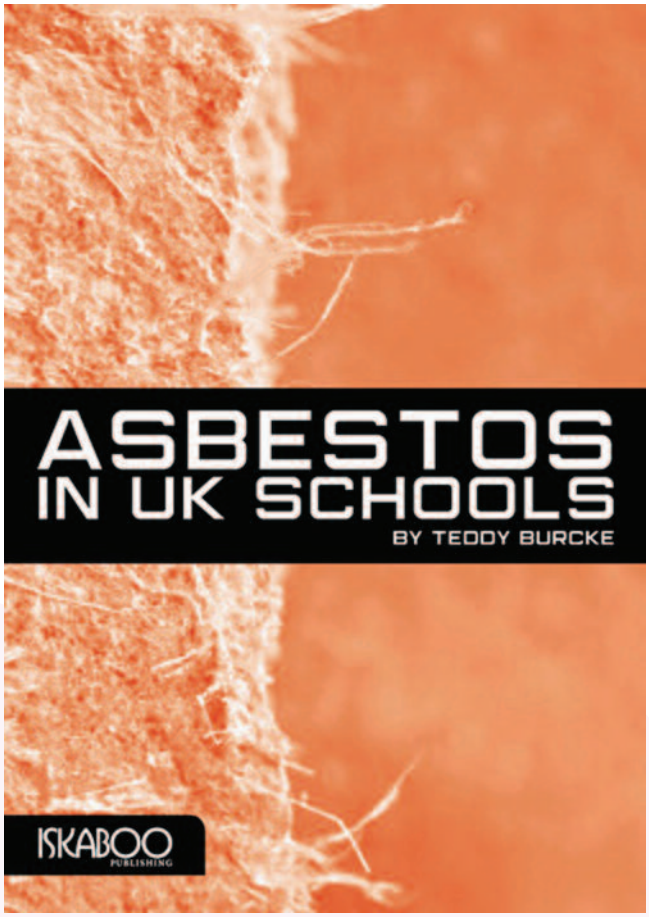
NEW REPORT ON ASBESTOS IN SCHOOLS

A new report, 'Asbestos in UK Schools' by Teddy Burcke has been released to highlight the alarming amount of asbestos that remains in the UK's post-war school buildings.

Asbestos in schools poses a deadly threat to teachers, other educational employees and especially pupils. There are now a rising number of deaths related to exposure to asbestos present in school buildings, and the magnitude of the problem may not be known for many years as asbestos-related diseases often take a considerable time to manifest themselves.

Asbestos in UK Schools reviews and clarifies the relevant information about the presence of asbestos within school buildings in the UK. The report examines the extent to which the problem is distributed throughout the country's schools, as well as the current legislation regarding asbestos management in schools. The report addresses the issue of acceptable exposure fibre levels, and it also assesses the views of relevant government and non-government entities such as trade unions and parliamentary groups.

You can purchase a copy of the full report at www.iskaboo.co.uk



MIST TRIAL OPENS FOR RECRUITMENT

Leicester is leading the development of the world's first molecularly stratified umbrella study, Mesothelioma Stratified Therapy (MiST).

This trial will utilise a molecular profiling panel to identify patients who are eligible for treatment. The second step will be to stratify patients for treatment, based on molecular eligibility. Patients would receive up to four different treatments sequentially. The third step will be to utilise genomic interrogation of the original biopsy tissue to understand why patients respond (or not) to the trial drugs and if they respond, what factors eventually lead to the emergence of drug resistance.

MiST will be a flagship, Leicester-sponsored clinical trial. Initially located in a single centre, the expectation will be that the study will be able to expand to multiple UK centres, with the potential to add promising new treatment arms and additional molecular stratifications.

For more details, contact MiSTmailbox@leicester.ac.uk.

Mesothelioma
Research Programme
LEICESTER

GET 'MORE' FROM MESOTHELIOMA UK

By Lorraine Creech, Mesothelioma UK Nurse Team Leader

The MORE (Mesothelioma Outcomes, Research and Experience) Survey commenced at the beginning of January 2019 and follows the previous Mesothelioma UK patient and carer survey undertaken in 2012.

So many developments in treatment and care have occurred since then and Mesothelioma UK is inviting mesothelioma patients to have the opportunity to describe what their experience of investigations, treatment and care have really been.

The survey will enable us to inform healthcare providers what is being done well, what could be improved and hopefully, where there are variations in treatment and care to be addressed. It will also assist 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.

We hope to receive 600 responses before completion of the survey in June 2019. Currently we have received in excess of 160 and our nurses are working very hard to make sure that all patients are aware of the survey.

If you would like to take part in the survey, please call our freephone information line on 0800 169 2409 (Mon to Fri 08:30 to 16:30) to get the contact details of your local Mesothelioma Clinical Nurse Specialist.

Your Mesothelioma Clinical Nurse Specialist will provide you with a unique patient identifier that you need to record in the survey.

You can either complete the questionnaire online or on paper. For more information, visit www.mesothelioma.uk.com/survey

Please help us to make a difference.

WELLBEING COURSE FOR ARMED FORCES PERSONNEL AND VETERANS

Armed Forces personnel and veterans who are living with cancer are being offered a week long, residential wellbeing programme by Odyssey Project Limited.

Odyssey runs short, deeply engaging courses based around outdoor activities and art, to enhance the mental and physical wellbeing of people living with cancer and their close dependents.

The places are funded by the Army Benevolent Fund and RAF Benevolent Fund and are available for the week of 12-17 May 2019. The meeting point is Shrewsbury Railway Station and from there participants will be taken, via various activities, to the accommodation.

Odyssey participants must be:

- over 18
- living with cancer (any type or stage)
- capable of walking at least 200m
- serving personnel, veterans or dependants from any part of the UK

The exact programme for the week is not revealed to the participants and that process of approaching the unknown and discovery, as well as the journey through the week, is something that works really well and helps participants to come to terms with uncertainty.

If you would like to find out more about this opportunity, please speak to your Mesothelioma UK Clinical Nurse Specialist who will be able to refer you if you meet the criteria.

www.odyssey.org.uk

MILITARY MESOTHELIOMA EXPERIENCE STUDY (MIMES)

The MIMES research study is being conducted as part of the wider Mesothelioma UK - Supporting our Armed Forces initiative. This aims to raise awareness of the disease and establish a comprehensive shared approach to providing mesothelioma information and support for armed forces personnel and veterans.

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

The School of Nursing and Midwifery at the University of Sheffield is conducting some research to explore the experiences of British Armed Forces personnel/ veterans with mesothelioma and their family members.

The research engages with health professionals and support agencies to identify how services can best meet the health and support needs of these patients and their families. The project involves interviewing people with a mesothelioma diagnosis who have also served in the armed forces. Family members are also interviewed.

So far the MIMES:
- has recruited and interviewed six participants
- has conducted some initial analysis of these interviews before recruiting additional participants
- has welcomed Stephanie Ejegi-Memeh as the new researcher on MIMES

Please contact Angela Tod at a.tod@sheffield.ac.uk or call the Mesothelioma UK freephone information line on 0800 169 2409 to register your interest.

BURNS NIGHT CELEBRATIONS

Burns Night was celebrated at two of our support group meetings in January. The Leicester MELU and the Anglia Asbestos Disease Support Group meetings both celebrated the Scottish poet with a piper, while guests were served traditional haggis with neeps and tatties.

Our busy ambassador, Brian Wallis, attended both events to talk about our Supporting Our Armed Forces project.

RAISING AWARENESS

Our Clinical Nurse Specialist for the Armed Forces, Helen Wilkes, and HASAG Asbestos Disease Support's Benefits Advisor, Lisa Booth, attended the HMS Excellent Health event last month to talk about Mesothelioma UK's Supporting our Armed Forces service. It was a busy day, seeing not only serving naval personnel but also civilians who work on the naval base. Many visitors to the stand weren't aware of the dangers of asbestos and didn't realise that buildings in which they work today could still contain asbestos.

BENEFITS AND PAYMENTS

Between April and December 2018, our benefits advisors have helped 39 armed forces personnel and veterans to access lump sum payments and annualised benefit payments. The benefits system can be very complex for those who are serving/have served in the Armed Forces but with the support of our advisors, Caroline Barry and Lisa Booth, those patients have been able to access a combined total of **£5,180,000**.

FUNDRAISING

BEN BRACKENBURY AND ANGUS OWENS - YORKSHIRE THREE PEAKS CHALLENGE - RAISED £887.50

Sadly, we lost our lovely Grandma Celia to mesothelioma. We carried out the 23 miles Yorkshire Three Peaks Challenge in September 2018 in memory of her. Her chosen charity would have been Mesothelioma UK. This charity did a fantastic job supporting my Grandma and our family. Our Grandad George took part in 'Grow A Mo' for Meso in 2016 when our Grandma was first diagnosed with mesothelioma and he grew a beard to help raise awareness and funds. He raised **£320.00** which we added to our **£567.50**.

TEAM FI - BEACH HEAD MARATHON - RAISED £14,000

We formed 'Team Fi ' to support our beautiful friend and team member Fiona Holmes. We think Fiona is best explaining this:

Hello lovely friends and family. As you all know I have Mesothelioma Sarcomatoid - an aggressive and terminal asbestos-related cancer. Important research funded by Mesothelioma UK into cures and prolonging patients lives is not government funded and they rely almost entirely on donations by people like you.

When Sarah first told me she was planning to run the Beachy Head Marathon which is the second hardest off road marathon, in the UK, I told her she was crazy! But when she also then told me that she was running along with Sue, Charity, Steve & Holly and were running it for me and for Mesothelioma UK, I told her it was a great idea!! Holly is also running in memory of a close family friend, Jim Walker, who was also diagnosed with mesothelioma.

Of course, I would have loved to have had the choice whether or not to run this event with them, but my illness has sadly taken this and many other opportunities away from me. However, I am going to experience all of the ups and downs with them every step of the way and share the pain (via text message and WhatsApp!!). She said that when things were tough, they would think about the reasons why they were doing this challenge... and push on.

Any donation goes directly to the organisation that can help make a difference, by funding the research to find a cure, and support patients of this disease, which are on the increase.

EMMA & LOUISE OGLEY - 35 MILES TEN TORS HIKE & CAMP ACROSS DARTMOOR - RAISED £248.75 IN MEMORY OF GRAHAM MAKIN

My grandad, Graham Makin, died on 28 December 2017, aged 73. In October 2016, he found out he had terminal cancer, caused from working with asbestos. My grandad didn't want to die and couldn't bear the thought of leaving my grandma. He had six months of chemotherapy treatment followed by trials at Leicester. He never gave up the fight and fought it right until the last week.

In his memory we took part in a 35 mile walk across Dartmoor to raise money for Mesothelioma UK. We want to help to try and find a cure.

MICHAELA LAKE - GREAT NORTH RUN - RAISED £630 IN MEMORY OF HER DAD, MICHAEL ARTHUR CROSS

My dear dad was diagnosed with mesothelioma in November 2016. He fought bravely but lost his battle in July 2017, aged 66. Watching the man suffer who was always the life and soul of the party, who was always the one running around after everybody else, was the most heart-breaking experience of my life. He was a true gentleman, my super hero and worked hard his whole life for his family, only managing just over a year of retirement when he deserved so much more.

He got this cancer just going to work and providing for his family. A cancer that should never have happened in the first place as the effects were known but still used in industry. Mesothelioma is hugely under-funded and lack of research means that it is terminal. There are so many hard-working men and women who may have been exposed to this in their workplace and it is still in many buildings and schools today.

SALLY REEDMAN - SENIOR CAPTAIN'S CHARITY DAY AT LITTLE LAKES GOLF CLUB - RAISED £1,508.50

On 20 September, a wonderful day was had raising funds for Mesothelioma UK at our local golf club. Little Lakes Golf Club in Bewdley, Worcestershire, kindly supported us with a Senior Captain's Day organised by their senior captain, Mr Michael Crouch who is also my cousin's husband.

They had over 100 participants and also supported the raffle during the event. In total, they managed to raise a huge amount. I was there to represent Mesothelioma UK as my husband Michael Reedman passed away having suffered with this awful disease six years ago. We are very grateful for the support of Little Lakes Golf Club in helping us to raise this amount of money as well as raising awareness throughout the club members of this terrible disease.

LOUISE MCINTYRE - SKYDIVE CHALLENGE DUBAI - RAISED £645 IN MEMORY OF HER DAD, GERARD MCINTYRE

Mesothelioma UK is a charity very close to me and my family. My dad was diagnosed in the beginning of July 2013 and died in August 2013 at 52 years of age. There is not enough medical knowledge or research to help find a cure for this disease yet so thankfully with your help, I was able to raise a lovely sum of money to help towards the charity achieving their aims of helping those living with mesothelioma.

It was a joke with Dad that jumping out of a plane should have been on his bucket list but he didn't manage it, so for five years I have said I will, and now I have.

CARL SHEPHERD - IRON BUTT CHALLENGE, 24 HOUR 1,000 MILE BIKE CHALLENGE - RAISED £1,233 IN MEMORY OF PAULINE HUNTER

The day after hearing the very sad news about Pauline, I was asked, by chance, if I wanted to take part in an Iron Butt event - a 1,000 miles bike run in 24 hours. A lot of the route is through Scotland and with the very Scottish Pauline in mind, I accepted.

All those who knew Pauline, loved her fun approach to life and her infectious laughter, even after heartbreak for her earlier on. We were all made up for her that she had found love and happiness again with Tommy. He was a perfect match for her crazy ways. Now she has been tragically taken from Tommy, this is just a small gesture to show how much we enjoyed her company. RIP crazy, funny lady.

RACHEL HICKS & NICOLA MAIERS - GREAT SOUTH RUN - RAISED £594.88

THOMAS CROLLA - GROW A MO FOR MESO - RAISED £168.75

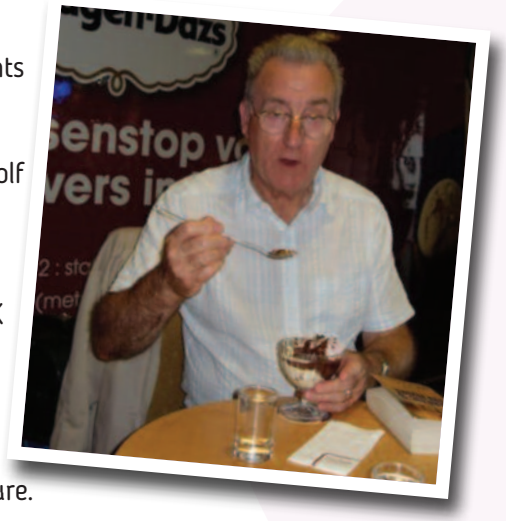
Thomas took part in our Grow a Mo for Meso campaign and grew a moustache during November.

1st November 30th November

ROB GOLDSMITH - CAPTAIN'S CHARITY 2018 - OAKLAND PARK GOLF CLUB RAISED £10,113.18 IN MEMORY OF RON PAGE

Ron Page was my father-in-law and friend. This horrible disease ended his life far too early but I will always remember the fun we always had at family events and holidays. A true gentleman and a loving husband and father, his gentleness and humour are sadly missed.

A series of fundraising events during my year as Captain of Oakland Park Golf Club has raised much needed money for Mesothelioma UK to help people with this horrible cancer caused by asbestos exposure.



MELISSA PAGE 50TH BIRTHDAY CHALLENGE - RUNNING EVERY WEEK FOR 50 WEEKS RAISED £2,092.83

I was happy to have reached my 50th birthday in good health but I am conscious that there are 2.5 million people living with cancer in the UK today, and as more people live longer with their cancer, this number is set to grow to four million by 2030. In my own circle of family and friends, my grandmother died of cancer, my mother had breast cancer and my aunt has mesothelioma. Everyone knows someone who has been affected by this disease.

So I set myself a challenge for my 50th birthday - run, jog or (if necessary) walk 50km every week for 50 weeks - to raise money for Mesothelioma UK which is now complete.

LEE BERNARD - SPARTAN RACES CHALLENGE - RAISED £1,023.75 IN SUPPORT OF HIS DAD

I took the challenge of completing the Spartan Races in one calendar year. The first race is the April 6k Spartan sprint where I finished 751 out of 2456 runners, which is not bad! Then, the 12k Spartan super in July and topped off with the 24k Spartan beast in October.

I've been in training since June 2017 and I wanted to raise money to support this amazing charity who provide help and support for patients of mesothelioma and their families. Mesothelioma is a cancer caused by exposure to asbestos. A few years ago it was relatively unheard of and sadly it is becoming more prevalent in recent times, particularly amongst individuals working in the building trade through the 70s, 80s and 90s.

My amazing Dad has been fighting mesothelioma since last May.

CHRISTOPHER QUINN - CHESTER MARATHON - RAISED £1,097.14 IN SUPPORT OF HIS DAD, JOSEPH QUINN

I chose to do this fundraising event for Mesothelioma UK on behalf of my Dad, Joseph Quinn, who has recently been diagnosed with mesothelioma caused by asbestos exposure during his working life.

This is the biggest challenge of my life, physically and mentally. However, I believed my reason was bigger than the challenge itself and for that reason, it was going to be the only thing that got me through when it got really, really tough.

My aim for the challenge was to raise money in honour of my Dad and with the help of my supporters, I raised **£1,097.14**.

SARAH HOLLAND - GUINNESS WORLD RECORD ATTEMPT SKYDIVE - RAISED £687.50 IN MEMORY OF DEREK HOLLAND

Sarah was a participant in the Guinness World Record 2018 attempt for the 10,000ft Tandem Skydive.

PAUL LYNES - NEW YORK MARATHON - RAISED £2,372.09 IN MEMORY OF FATHER, DAVE LYNES

I ran the New York Marathon in November 2018 in memory of my Dad, Dave Lynes. I raised money for Mesothelioma UK, a charity committed to patients of the asbestos-related cancer that took Dad from us too early, back in 2007.

Dad was dedicated to his family and his long career as a police officer. He also managed to find the time to train for and complete two London Marathons. He's my inspiration for running the New York race, my very first marathon.

AIDEN PARRY – MINI TOUGH MUDDER - RAISED £575.25

My husband's Dad and my son, Aiden's Grandad John was diagnosed with mesothelioma and has been fighting a long and hard battle over the past year or so.

Aiden wanted to raise money to help and support not only what his grandad is going through, but others that are also fighting this horrible disease. So he ran, clambered and waded through a mile long assault course in support of his lovely Grandad John.

Thank you to all those that supported Aiden.
Aiden's mum, Laura Parry.

HAYLEY HAWKINS & TEAM - CARDIFF 10K RUN - RAISED £268.75

Lauren, Angharad, Hayley and Hannah from the Hugh James Asbestos Team took part in the Cardiff 10k in September 2018 to raise awareness and much needed funds for Mesothelioma UK.

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BECKY & MARTIN RICHARDSON - ROBIN HOOD HALF MARATHON - RAISED £1,137.25 IN MEMORY OF ROGER DREW

In September 2018, we ran the Robin Hood Half Marathon in Nottingham to raise money for Mesothelioma UK. In 2014, a close friend sadly passed away from this horrible disease and the charity was incredibly supportive, both throughout and after his suffering. We wanted to help Mesothelioma UK continue its invaluable work by raising any amount possible, so thank you to all those who supported and sponsored us.

TOM RAVENSCROFT - COURCHEVEL X-TRAIL RACE - RAISED £4,485.78 IN MEMORY OF BRIAN MARREN

Once again I decided to run the X-Trail race in the French Alps ski resort of Courchevel. I was running in memory of my father in law, Brian Marren, who passed away from mesothelioma in 2011 and whose favourite place in the world was Courchevel. A big thank you to my supporters.

KIRA SWANNELL AND FAMILY - SWIM A MILE FOR A SMILE - RAISED £200 IN MEMORY OF JAN STEVENS

In July, the whole family took part in a mile long charity swim to raise money for two charities very close to our hearts. The youngest participant turned four on the day and the oldest participant will be 77!

We were looking forward to having a bit of fun in the sun whilst raising as much money as possible. Unfortunately, it rained, but that didn't stop us going ahead and having fun.

MARTIN BLACKMAN - BRIAN'S MEMORIAL WALK - RAISED £402.50

2018 was the 10th anniversary of our Dad, Brian's passing and we wanted to mark this important event by raising monies for Mesothelioma UK. Brian was a wonderful husband, dad, grandad, son, brother, uncle and friend to many. He was warm, fun, hard-working, generous and kind to those he cared for and made an impression on anyone he met. His love for life and determination to enjoy every moment of it kept him strong right up to the end.

He is greatly missed by all who knew him and therefore to help others suffering from the effects of asbestos and their families, we wanted to raise money for the charity that supports them.

Thank you for all those who supported us and for donating.
Chris, Tricia, Debbie, Fiona and Greg.

EMMA STREET AND TEAM - PINTLESMITHS YORKSHIRE 3 PEAKS WALK - RAISED £2,051.25

Rachel, Amy, Sophie and Emma love a challenge so we walked up and down three Yorkshire peaks (40km) to raise money for this great charity.

Thanks everyone for all your kind donations. There was sun, wind, rain and amazing scenery. We talked nonstop. We arrived back just as the dark set in. Such a memorable day for a great charity.

MARC DYER - BOURNEMOUTH MARATHON - RAISED £382.50 IN MEMORY OF WIFE'S GRANDFATHER, CHRIS YEATS

In November, we sadly lost my wife's grandad, Chris, to mesothelioma. Last October I ran the Bournemouth full marathon and was lucky enough for Chris to come and watch, and show his support as he always did. Chris was, and still is a massive part of our family and this year, I would like to do run the half marathon in his memory and to hopefully raise some more money for a very deserving charity.

RACHAEL FRETTER - NORWICH RUN - RAISED £1,491.25 IN MEMORY OF FATHER, DAVID SPOONER

In August 2016, dad was unfortunately diagnosed with mesothelioma. This came as a huge shock and dad faced it in his own way. However, on 2 January 2017, his brief battle with cancer came to an end.

I now want to do what I can to raise awareness of mesothelioma and raise funds to help others who have this terrible disease. I live in hope that one day a cure is found!

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.

METRO SAFETY - FUNDRAISING EVENTS 2018 - RAISED £1,775.00

Metro Safety is firmly in support of making a worthwhile contribution to the wider community. Over the years we have been involved in many fundraising events and community initiatives. For the last 12 years we have also provided CPD events free of charge to help property professionals from a variety of sectors gain a greater understanding of fire, health & safety legislation.

We are now asking those who wish to attend our seminars to join with us and help make a difference by making a donation to our nominated charity, Mesothelioma UK. All the money raised from the CPD event will go directly to Mesothelioma UK.

Fundraising is hugely important to Mesothelioma UK. Without people doing events, running marathons, climbing mountains and donating in all the other ways that you can, Mesothelioma UK wouldn't exist.

NIC BAXTER - ROBIN HOOD HALF MARATHON - RAISED £1,062.52 IN MEMORY OF FATHER, MICK MATHERS

I ran the Ikano Bank Robin Hood Half for Mesothelioma UK because my dad's fight lives on. Always!!

EDWARD JOY AND TEAM - MANCHESTER 100KM BIKE RIDE - RAISED £858.75

In September, Katrina London, Nick Jackson and Ed Joy from Irwin Mitchell Solicitors in Manchester raised money for Mesothelioma UK by cycling the Manchester 100km.

JESSICA BATHGATE - SNOWDEN WALK 28 JULY 2018 - RAISED £482.50 IN SUPPORT OF HER MUM

A group of us climbed mount Snowdon to raise money and awareness for this amazing charity who help people like my mum.

Contact Mesothelioma UK:

Freephone

0800 169 2409

info@mesothelioma.uk.com

www.mesothelioma.uk.com

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 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

International Workers' Memorial Day
28 April 2019
Theme for 2019 is dangerous substances - get them out of the workplace
www.tuc.org.uk/workers-memorial-day-0

Muffins for Meso
Running throughout May
Contact jill.lemon@mesothelioma.uk.com for a fundraising pack

Isle of Wight Coastal Path Ultra Challenge
4-5 May 2019
www.ultrachallenge.com/isle-of-wight-challenge

London to Brighton Capital to Coast Ultra Challenge
25-26 May 2019
www.ultrachallenge.com/london-2-brighton-challenge

Action Mesothelioma Day
5 July 2019
Events will be held around the country and Mesothelioma UK's event will be at Leicester Cathedral.

Mesothelioma UK Patient and Carer Day
4 October 2019
Imperial Hotel, Blackpool

Please send details of any local events to meso@sandstarcomms.com so that we can add them to the Meso UK website.

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