Dear Mesothelioma UK Supporters

You will see from the content of the newsletter that the charity’s activity continues to increase. We have an incredible, dedicated team here at the charity who are so proud of all that is being achieved and we simply couldn’t do it without your support, for which we are hugely grateful.

Mesothelioma UK is supporting clinical services, national audit, patient travel, education and training, is soon to establish specialist support and information for military personnel, and of course, our ‘tour de force’ has to be our growing team of specialist nurses.

Nurse 13 Sarah Morgan has recently taken up her post in Carmarthenshire, Wales and we have a call out for expressions of interest for more nursing posts.

Each nurse is supported to establish themselves as a mesothelioma expert with a local, regional and national responsibility. Mesothelioma-specific education, training and networking is crucial to this but the dividends of investing in their expertise is immeasurable to people living with and affected by mesothelioma, and increasingly to the NHS teams across the UK providing treatment and care.

Mesothelioma UK is eager to have 28-30 nurses around the UK, all linked in to the best expert training and support available so that they can be a beacon for everything related to the disease within their regions. It strikes me that for rarer diseases, this successful model of partnership working between a charity and our amazing NHS is the way forward.

Another area in which we are keen to progress quite rapidly is funding for research. We currently support an annual basic science/clinical research grant, administered on our behalf by the British Lung Foundation and a second one through the National Lung Cancer Forum for Nurses (this year funded by the Pat Stone Trust). Of course, we are eager to do more. Research is the only means of finding better outcomes and a credible way to improve people’s experience of care.

Providing insight and education into the results of clinical research and availability of trials is essential. This month, over 120 health care professionals (plus other delegates) from across the UK attended the joint Meso UK/British Thoracic Oncology Group meeting - The Essential Mesothelioma Update 2017. Keeping our NHS workforce up to date is crucial if we are to ensure equal access across the country to the best trials, treatment and care we have available.

If you would like to know more about Mesothelioma UK’s work, our vision or if you would like to get involved or support us in any way, please do not hesitate to contact the charity by any of the usual means.

Happy spring everyone.

Liz Darlison

Action Mesothelioma Day takes place on Friday 7th July. If you are taking part, please send details to us and we will share them on our website
Introducing Bob McLaren, new ambassador for Wales

My name is Bob McLaren. I currently live in Poole in Dorset and will be moving to south Wales in the near future to be nearer family and to better carry out my role with Mesothelioma UK as their Ambassador for Wales.

I have one son and three daughters. I have been married twice – my first wife, Helen, died in March 2007 from Acute Myeloid Leukaemia.

My second wife, Jo, died from Peritoneal Mesothelioma in September 2016.

During Jo’s six-year battle with this entirely preventable cancer, there were many pitfalls in obtaining the best effective treatments to extend her life. The fact that Jo had a terminal cancer didn’t seem enough for her to obtain the best medicine and we had to jump through hoops and be quite forceful at times to get the correct drugs for her.

Since Jo died and I retired, I wanted to do something to help others who suffer with this terrible disease. My role with Mesothelioma UK will hopefully allow me to raise the profile of mesothelioma and of the charity in Wales.

I will do my very best to support the service and find collaboration opportunities in an international registry. Patients may benefit from surgery if all their macroscopic disease can be completely removed and the abdomen washed with hot chemotherapy. Sometimes if there is a lot of abdominal swelling from ascites with disease on the omentum, a major tumour debulking procedure can help control symptoms and improve quality of life. Unfortunately, the majority of patients are not suitable for this approach and are best treated with systemic chemotherapy. We use combination of CT scans and keyhole laparoscopy procedures to help select those who may benefit.

In July 2015, NHS England concluded there was insufficient evidence of the effectiveness of this treatment for patients with abdominal mesothelioma and so this treatment is not currently routinely funded by the NHS.

Basingstoke & North Hampshire Hospital is working with The Christie, Manchester Good Hope Hospital in Birmingham and The Mater Hospital, Dublin and have set up a National Peritoneal Mesothelioma Multidisciplinary Team (NPMMDT), bringing together leading clinical specialists to discuss every referred patient, focusing on their presentation, diagnosis and treatment options and providing recommendations.

The team aims to gain consensus on clinical approach and to gather evidence on the effectiveness of NPMMDT outcomes and surgical treatment to support NHS England in its commissioning decisions.

The team first met in July 2016 and have held six subsequent National Peritoneal Mesothelioma MDT meetings, discussing 49 patients and making recommendations as to most appropriate treatment. The NPMMDT has recommended four patients for surgery and others for chemotherapy in the first instance, with possible surgery as a subsequent treatment option.

We are seeing a growing number of referrals to the National Peritoneal Mesothelioma MDT and we anticipate making treatment recommendations for over 100 patients a year initially and crucially, collate the outcomes of any treatment provided.

The event was organised by MARF in collaboration with the National Cancer Institute (NCI) and several of its clinical nurse specialists attended. Leading cancer researcher, Professor Dean Fennell, PhD FRCP, from the University Hospitals of Leicester NHS Trust who works closely with Mesothelioma UK, was one of the guest speakers.

The Symposium was geared to attendees from all walks of life, including patients and their families, advocates, medical professionals, and those who have lost loved ones to mesothelioma. The Symposium provided a setting for everyone in the mesothelioma community to come together and take part in both scientific sessions and community conversations. Mesothelioma experts came together to share their work and find collaboration opportunities in an effort to speed up mesothelioma advances.

More details about the team’s experiences at the Symposium will be in the next issue of this newsletter.

Leaving a gift in your Will

Mesothelioma UK’s priority is to be there for you and your loved ones. It is only through fundraising and the generosity of our supporters that we are able to do this. An important source of funding for many charities is gifts left in wills, also known as legacies.

We feel a special sense of privilege whenever we are mentioned in a will. Receiving a gift in a will is an honour; it reminds us of the commitment and generosity of our supporters, and helps us to plan for the future.

No matter how big or small a donation, it helps us to achieve our aims of improving the care and treatment of people with mesothelioma.

• A gift of £50.00 will cover the Mesothelioma UK helpline and email service for one hour and £50 will pay for 1 day

HASAG donates £20,000 to Mesothelioma UK

The HASAG Asbestos Disease Support group for sufferers in the south of England has generously donated £20,000 to Mesothelioma UK.

The donation will be used to fund research into the treatment of the asbestos-related cancer mesothelioma and for the care of existing patients. The money was raised from HASAG’s Action Mesothelioma Day in 2016 and other related events.

HASAG has supported Mesothelioma UK for over three years with fundraising now passing £55,000. This support has enabled a number of initiatives for mesothelioma patients in the south of England including the recruitment of a Clinical Nurse Specialist, Anne Moylan, who is team leader for Mesothelioma UK nurses across the south of the country, covering London, Wales, Cambridgeshire, Oxford and Plymouth.

Lynne Squirbs from HASAG said: “HASAG is a completely independent, campaigning organisation and thanks to the extremely generous and amazing support of our group, we continue to raise thousands of pounds for asbestos (meso and patient) support. This fundraising effort is vital and through the money raised for Mesothelioma UK in particular, we’ve been able to fund the appointment of a Clinical Nurse Specialist in Anne Moylan who has been amazing for mesothelioma patients in the south of England.”

“We hope to continue to keep this support going and help Mesothelioma UK to continue its great work into the treatment, care and support of mesothelioma patients across the UK.”

Liz Darlison, Mesothelioma UK Director of Services and Consultant Nurse, commented: “We can’t thank HASAG supporters enough for all of the great work that they do to raise awareness of, and provide support for this awful disease of mesothelioma.

“Their fundraising efforts have been pivotal in helping us to extend support for patients in the south, particularly through the recruitment of Anne who is providing first-hand support to patients, carers and families through clinics, events, as well as providing literature, advice and ongoing support.”
During a parliamentary debate, Kezia Dugdale - Scotland’s only mesothelioma Clinical Nurse Specialist - raised a point about the need for cross-parliamentary support and the importance of mesothelioma as a national issue. The debate focused on the need for more research, funding, and awareness to combat this deadly disease.

Mesothelioma in Scotland is a significant public health issue, with Scotland having the highest global incidence of mesothelioma. The disease is caused by exposure to asbestos, and the Scottish Government has acknowledged the need for increased funding and research to combat this epidemic. The debate included speeches from politicians and stakeholders, highlighting the need for increased awareness and support for mesothelioma patients and their families.

Meet Caroline Barry, our Benefits Advisor

Caroline Barry offers advice on benefits and support to mesothelioma patients and their families. She can be contacted at mesothelioma.uk@uhl-tr.nhs.uk or by email at caroline.barry@mesothelioma.uk

More on chrysotile

By Andrew James, Senior Associate with Hodge, Jones & Allen

During the debate, Kezia Dugdale highlighted the need for more research and funding to combat mesothelioma. She emphasized the importance of cross-parliamentary support and the need for increased awareness and support for mesothelioma patients and their families.

The debate also included speeches from politicians and stakeholders, highlighting the need for increased awareness and support for mesothelioma patients and their families. Thedebate concluded with a call for increased funding and research to combat this epidemic, as well as increased awareness and support for mesothelioma patients and their families.

Dr. Blyth believes that a hub-and-spoke model would transform mesothelioma care in Scotland, providing equitable and high-quality care, alongside support for patients and their families and the chance to pursue life-changing trials.

During a parliamentary debate, Kezia Dugdale highlighted the efforts of Julie Roberts and her family. Julie’s father and uncle sadly died of mesothelioma within six weeks in 2016. Her father Gordon was a joiner and had worked for one of Edinburgh’s biggest building firms. Her uncle Jim had been a plumber. Julie has become an advocate for patients and carers with mesothelioma and wants to ensure that her campaigning makes a real difference to their diagnosis and care. Kezia Dugdale has become aware of Julie’s story through her mutual support of Scottish Football Club, of which Julie’s father was a season ticket holder.

A month before the debate Kezia had welcomed a number of campaign groups including Living Individuals, Direct Services and Nurse Consultant at Mesothelioma Scotland, to the Scottish Parliament to discuss how much greater the situation is and what can be done to tackle mesothelioma in Scotland. The Mesothelioma UK five-year strategy, Dedicated to Making a Difference, focuses on the ongoing work of cross-parliamentary support for mesothelioma, including Liz Darlison, Director Services and Nurse Consultant at Mesothelioma Scotland focusing on:

- Raising public awareness
- Improving GP training
- Championing the hub-and-spoke model of a Scottish National Mesothelioma Centre based in Glasgow
- Increasing the numbers of Mesothelioma Clinical Nurse Specialists

Meet Caroline Barry, our Benefits Advisor

Because mesothelioma is an asbestos-related disease, it is often possible for patients to make an industrial disease compensation claim. Many people and their families, who have worked in public buildings where asbestos was used, have been placed at risk and, if diagnosed, may be entitled to compensation from their former employer or from the Government.

Caroline offers support to people across the UK and is available for home visits in the East Midlands.

As an advisor, Caroline has access to the specialist support services offered by the Citizens Advice Bureaux and has worked with patients and families with welfare benefits and debt management as well as applications for a lump sum compensation payment from the Government.

Caroline says: “For those receiving a diagnosis of mesothelioma it is absolutely devastating not only for them but also for their families and loved ones. Trying to work out benefit entitlement and what forms to fill in at such a time can be just too difficult and can appear overwhelming. I see my role as supporting mesothelioma patients with all aspects of identifying and applying for benefits and Government lump sum compensation along with resolving any problems that arise during the claim. Indeed, many people lose out on benefits because the application process seems too difficult or they simply don’t know that they have a right to make a claim. I believe passionately in helping people access the benefits to which they have a legal entitlement.”

Since June 2015 Caroline has helped over 250 patients and their families to claim a total of £251,865 in lump sum payments and around £1,716,026 in annualised benefits.

You can contact Caroline by telephone on the Mesothelioma UK helpline 0800 169 2409 or by email at mesothelioma.uk@uhl-tr.nhs.uk

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In the 1960s, faced with increasing scientific evidence that all types of asbestos caused mesothelioma, the asbestos industry sought to fight back in the same way as the tobacco industry and establish a scientific counter-argument. 85% of Canadian asbestos was mined at Quebec in the Thetford mines. They were the world’s largest producer of chrysotile or white asbestos. The vast majority of asbestos used worldwide was chrysotile, not blue asbestos. As the industry could no longer deny that asbestos caused mesothelioma they sought to change the discussion and blame blue asbestos (and later contaminants) as this would not greatly affect their profits.

In 1966 the Quebec Asbestos Mining Association (QAMA) was set up by Johns-Manville and other multi-national asbestos companies set up an organisation called the Institute of Occupational & Environmental Health (IOEH). It was financed with $2 million dollars and controlled by the asbestos companies. The aim of QAMA was to be "independent of any other institution – university or governmental – so that policy can be determined by the needs of the industry".

Professor J C McDonald of McGill University’s Department of Epidemiology testified as a paid expert witness on behalf of W. R. Grace and Company, which had supplied asbestos to the Canadian Forces during World War II. He was paid $1.6 million dollars to prepare his reports and findings favourable to its own interests. It was later shown that interest in the asbestos industry has funded and supported scientific institutes in order to prove the safety of asbestos and to continue use of asbestos. "Similar to the tobacco industry, the asbestos industry has funded and manipulated research to manipulate findings favourable to its own interests. It has set up front organisations claiming to be expert scientific institutes…they are, in reality, lobby groups promoting the continued use of asbestos."

However, experts continue to provide scientific “evidence” via industry funded research to support the continued sale of white asbestos. Asbestos is still mined and sold on the pretence that white asbestos is safe. These studies and others like them are quoted and used, have been placed at risk and, if diagnosed, may be entitled to compensation from their former employer or from the Government.

The asbestos industry has funded and manipulated research to manipulate findings favourable to its own interests. It has set up front organisations claiming to be expert scientific institutes…they are, in reality, lobby groups promoting the continued use of asbestos. The asbestos industry has used this evidence to oppose the EU ban on asbestos and to argue for the continued export of asbestos into the third world at the risk to the lives of workers and their families. McDonald had testified as a paid expert witness on behalf of many asbestos companies to defeat claims by injured workers and their families. The work by J C Wagner, published in 1960, linked mesothelioma to asbestos. His numerous lab studies over the next years showed that chrysotile produced the highest rates of mesothelioma, even at low doses and for those just living near asbestos mines.

In 1984 he dramatically changed his view and proclaimed “the innocence of chrysotile to humans” and began appearing as a paid expert witness in litigations on behalf of those lawyers representing asbestos companies. He emerged in 2000 that the US asbestos company Owens-Illinois had been paying Wagner for more than 15 years to deny the relationship between chrysotile and mesothelioma.

After retirement Wagner admitted that, from the mid-80s the asbestos industry set out to frustrate scientific discovery and complained that the whole scientific endeavour was “hacked” by lawyers.

In June 2012 the Joint Policy Committee of the Societies of Epidemiology (JPC-SE) stated “review of the epidemiologic evidence confirms that all types of asbestos fibre are causally implicated in the development of various diseases and premature death.”

“Similar to the tobacco industry, the asbestos industry has funded and manipulated research to manipulate findings favourable to its own interests. It has set up front organisations claiming to be expert scientific institutes…they are, in reality, lobby groups promoting the continued use of asbestos.”
If the closure goes ahead it will be a blow for mesothelioma sufferers who benefit greatly from the expertise that has been built up over many years by the DWP staff based in this office.

Phoenix House also administers compensation claims for ex-miners. In addition to ID2 claims, staff at Phoenix process linked benefits such as Constant Attendance Allowance, Exceptionally Severe Disablement Allowance and lump sums paid under the Pneumoconiosis (Workers’ Compensation) Act 1979 and 2008 Mesothelioma Scheme.

This is a niche area of the benefits system with complex benefit rules and a vulnerable client group, many of whom are elderly and have been newly diagnosed with a terminal illness. They need to be sure their claims will be dealt with sensitively and efficiently. Staff at Phoenix House tick all these boxes. Advice workers can reassure mesothelioma patients that the benefits to which they are entitled will be processed and paid within two weeks or so in nearly all cases.

The 70 workers in Phoenix House have built up a huge amount of expertise in these specialist benefits over many years. If the office closes the most likely result would be a deterioration in service, longer delays in processing benefit claims and increased uncertainty for mesothelioma patients.

Forum groups have developed an excellent working relationship with staff at Phoenix House and the people we help have benefitted greatly from their expertise and empathy. The Forum fully supports the DWP workers in their campaign to keep Phoenix House open.

We are asking supporters of Mesothelioma UK to help us defend this vital service for mesothelioma sufferers. Please:

- Write to your local MP demanding that Phoenix House stays open.
- Sign the online petition at https://www.change.org/p/department-for-work-and-pensions-save-phoenix-house-jobs-in-the-department-for-work-and-pensions
- Tell your local DWP branch to get involved.
- Send messages of support to PCS Cumbria DWP Branch, 22 Schneider Road, Barrow-in-Furness LA14 5DW
- Ask your local MP to press for action

It took a long time for me to acknowledge that I had cancer. I wouldn’t talk about cancer, just mesothelioma as all my life I didn’t want to be a cancer sufferer or someone who might think about dying. I was told to be realistic. It’s a sad truth. I fought cancer with my willpower and focus.

Several findings indicate that mesothelioma is characterised by a hypoxic micro-environment - the cellular area surrounding a tumour including blood vessels, immune cells and lymphocytes. The tumour and the surrounding microenvironment are closely related and interact constantly.

It is hoped that the study will allow researchers to identify hypoxamiRs (molecules which regulate how cells adapt to hypoxia) and their targets/pathways which could lead to the identification of novel therapeutic approaches to treatment.

After identifying the hypoxamiRs, the project aims to undertake early phase clinical trials to test the effects of modulating these molecules and their related pathways.

Longer term, there is potential for personalised treatment of mesothelioma patients by specifically targeting the hypoxic component of their tumours.

Treatments with miRNA antagonists/agonists for mesothelioma are currently being tested in early clinical settings so the translation of results on hypoxamiRs are expected to be announced soon.

ARCA Members donate £22,000 to Mesothelioma UK

Members of the Asbestos Removal Contractors Association (ARCA) have over the years raised funds for a number of charities mainly through social events and auctions.

Last year ARCA opened up opportunities for more members to participate by holding a Charity Week. During this week, many member companies and staff got involved in lots of ways to raise funds for the Association’s two chosen charities.

The UK has the highest incidence of mesothelioma in the world, and it continues to rise. Currently over 2,000 people are diagnosed and whilst the treatment options are increasing, hopefully improving outcomes too, the disease remains incurable.

People think it’s only an old person’s illness but that is not true. We have young people with the disease who must have come in contact with asbestos in school or through DIY as their parents renovated their home.

I know how hard it is to tell your story and to draw attention to your life. We do it, though, and we should tell our stories as we have to show people the human side to mesothelioma.

Read some personal stories from patients and their families on the Mesothelioma UK website at www.mesothelioma-uk.com

Mindfulness - be kind to yourself

By Anne Moylan, Team Leader and Clinical Nurse Specialist

Being diagnosed with cancer, or caring for someone with cancer can be overwhelming and stressful. Some people find seeking alternative ways to cope with these feelings can be useful.

Traditionally we have turned to strategies such as counselling or cognitive behavioural therapy to help but in the past few years, there has been increased interest in non-medication based strategies for supporting people with cancer and, as a result, meditation has become increasingly popular.

One of the meditation therapies that has a growing number of supporters is Mindfulness. Mindfulness is a process of maintaining a moment-by-moment awareness of our thoughts, feelings and surrounding environment. It allows you to focus on your thoughts and feelings without being too overwhelmed by what is going on around you or happening to you. It is a form of meditation that can be done while sitting and, although it can take practice to focus on the present moment and shut out the busy world around them, many people find it can help relieve stress and help them to cope with symptoms like pain, difficulty sleeping, tiredness and nausea.

Many support centres, clinics and hospices run Mindfulness sessions or there are many apps that can be downloaded onto smartphones or tablets that will guide you through the process. Ask your clinical team about the availability in your local area if you would like to explore this further.

Rehabilitation for lung cancer and mesothelioma patients

Keeping fit and active can be a challenge for people with lung cancer or mesothelioma. King’s College London and the CoeY Saunders Institute are conducting research into a rehabilitation service for people with these diseases.

Many support centres, clinics and hospices run Mindfulness sessions or there are many apps that can be downloaded onto smartphones or tablets that will guide you through the process. Ask your clinical team about the availability in your local area if you would like to explore this further.

Keep Phoenix House benefits office open! By Graham Dring, Chair, Asbestos Victims Support Groups’ Forum UK

Phoenix House in Barrow, Cumbria has been earmarked for closure in March 2018 by the Department for Work and Pensions (DWP). Phoenix House is a specialist benefits office that deals with all Industrial Injuries Disablement Benefit (ID2) claims for people diagnosed with mesothelioma and other asbestos diseases throughout the country.

So much awareness of cancer is being raised and we recently celebrated World Cancer Day 2017. I couldn’t keep up with Twitter as people tweeted all day long about their experience of cancer.

Addressing hypoxia as a new target for treatment of asbestos-induced cancer

Professor Luciano Mutti, Chair in Cancer Research, School of Environment & Life Sciences, University of Salford successfully applied for a grant from Mesothelioma UK and the British Lung Foundation for a study into targeting hypoxia as a treatment for mesothelioma.

World Cancer Day
By Mavis Nye, Meso Warrior, www.onestopmesothelioma.com

Hypoxia is a deficiency in the amount of oxygen reaching the tissues. In particular, mesothelioma cells express high levels of the hypoxia biomarkers CAIX, GLUT1, MCT1/MCT4 which are related to a poor prognosis and treatment resistance.

Several findings indicate that mesothelioma is characterised by a hypoxic micro-environment - the cellular area surrounding a tumour including blood vessels, immune cells and lymphocytes. The tumour and the surrounding microenvironment are closely related and interact constantly.

It is hoped that the study will allow researchers to identify hypoxamiRs (molecules which regulate how cells adapt to hypoxia) and their targets/pathways which could lead to the identification of novel therapeutic approaches to treatment.

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Can you help with the research?
If you have experience of lung cancer or mesothelioma and are interested in this area of study, please get in touch to find out more. Contact Jo Bayly on 0207 848 5679 or email joanne.bayly@flcic.ac.uk
MesobanK – A Mesothelioma Tissue Bioresource
By Jacki Gittins, Project Manager

MesobanK is a mesothelioma tissue bioresource, based at Papworth Hospital NHS Foundation Trust, collecting tissue and blood samples from patients all over the UK. MesobanK supplies researchers these samples to use in mesothelioma and asbestos related research.

Originally funded by the British Lung Foundation and Mick Knighton Mesothelioma Research Fund, we have very recently received funding from the Victor Dahdaleh Foundation ensuring we can continue to support research for the next four years.

We work on a number of areas – building Tissue MicroArrays (TMAs) with Formalin Fixed Paraffin Embedded (FFPE) tumour samples, prospective collection of blood, pleural fluid and tumour samples from patients newly diagnosed with mesothelioma, and the creation of novel cell lines.

Tissue Microarray (TMA)
A TMA is an incredibly useful tool for researchers. Small cores (0.6mm diameter) are taken from the tumour samples (FFPE) of many hundreds of patients and remounted in one block. This block is then thin cut to give researchers access to multiple samples on one slide (see diagram below).

There are samples from almost 1,000 patients that have been sorted and processed into what will be the largest mesothelioma TMA, available to researchers across the world.

Having multiple tumour samples available from many different patients in such a concise format allows researchers to use large numbers of samples in an identical manner very quickly and easily, allowing a single experiment to be undertaken simultaneously on many hundreds of samples.

Samples of mesothelioma tumour, stored as FFPE blocks, have been gathered from the archives of NHS Hospitals across the UK. This gives a huge breadth of samples and encompasses all subtypes of the disease.

Fresh Tissue Samples
Patients presenting to clinics in 14 hospitals in the UK are approached for consent to donate samples to MesobanK. Not all of these patients will be diagnosed with mesothelioma – some may never be diagnosed, but others may be diagnosed within a few years and samples from these patients may be very valuable to researchers. Where possible, tumour blood and pleural fluid samples are taken and processed and stored. Between January 2015 and January 2017 the number of patients donating samples has increased by 350%.

Cell Lines
Tumour cell lines are essential tools in the effort to develop therapies against cancer. The currently available mesothelioma cell lines were generated over the previous twenty years and have been maintained in culture for some time. Keeping cell lines for such a long time may mean that their effectiveness as tools for developing new anti-cancer treatments is reduced and so cell lines are being developed from new sources. MesobanK is working with two successful companies and in order to date 20 novel cell lines are available for research use. The demand for samples of these cell lines is high and discussion is underway to try to produce more new lines for researchers to use.

Open for business
A number of research groups have requested tissue and blood samples collected by MesobanK; samples of blood and tumour and been used in academics in UK universities and, in separate work, cell lines have been used for research into new medicines.

The samples currently being collected will support research over the next year at least, and we hope that MesobanK will facilitate and stimulate new ideas and avenues of research into mesothelioma that will lead to further research projects. We are open to discussions regarding bespoke sample collections and would invite researchers interested in using existing or future samples to contact us so that we can discuss requirements as early as possible.

Our long-term aim is that work using MesobanK tissue samples will translate into new treatments for patients with mesothelioma with the aim of improving survival rates, not just in the UK but across the globe. The new funding will allow MesobanK to expand into other countries and to continue to provide a lasting legacy for mesothelioma research for many years.

www.mesobank.com
Twitter: @Mesobank

Update on Asbestos in Schools (AiS) Campaign
By John McClean, AiS Co-ordinator and JUAC Chair

I cannot be the only long-term campaigner on mesothelioma and asbestos-related diseases to sometimes feel that not only are gains in gains for families and victims, but that history appear to be on a loop. It seems that you need to educate some participants on the core issues surrounding asbestos exposure and its consequences yet again.

Obviously, governments change and with that so does the approach to how to deal with asbestos in schools. We are used to minor changes but when whole departments change personnel and your initial meeting with them requires you to travel your core message to get up to speed with their brief, then you wonder if progress can ever be made properly.

However, with this frustration also comes some optimism - occasionally!

My predecessor in the AIS campaign, Michael Lees, who got involved in initiating the campaign when his wife, Gina, a teacher, died of mesothelioma, wrote movingly last year in the Tenth Edition of the British Asbestos Newsletter on the 30 years of neglect in dealing with asbestos in our schools.

While Michael has deservedly retired from the campaign, another campaigner, Lucie Stephens, who lost her year 13 student Sue, and another teacher, last year, has started a petition to raise awareness of the issue in UK schools, and get it taken more seriously. The petition can be found at: https://you.31343333.org.uk/petitions/protect-our-children-and-teachers-from-asbestos-exposure-in-schools.

There is an acknowledgment that the problem is ‘potentially’ serious and that new approaches to training, information and air monitoring need to be examined.

As always though, we live in a political world where funding issues, not least for overall education, pupil performance and establishing new schools, all impact on the issue we are most concerned with.

This is a long-term campaign - things do not change at great speed but change does occur, through both individual and collective campaigning. Yes, sometimes it can be frustrating but we have little choice but to continue.

Royds Withy King launches the Clifford Lloyd Education Fund
Mesothelioma UK gold sponsor, Royds Withy King, is offering discretionary £250 bursaries to professionals involved in the care and treatment of patients with mesothelioma and lung cancer.

This is to assist with the costs of attending the National Lung Cancer Forum for Nurses and the British Thoracic Oncology Group annual conferences.

The fund is in memory of their late client Clifford Lloyd, who sadly died in 2012 from mesothelioma. Royds Withy King has set up the education fund as a tribute to him.

If you are interested in applying for a Clifford Lloyd bursary please see the application form on Royds Withy King’s website: www.roydswithyk.com/asbestos-bursaries/

Developing central registry for patients

Sadly, although 2,500 cases of mesothelioma are still being diagnosed each year only a handful of patients become involved with available clinical trials. Contacting cases of mesothelioma early after the initial diagnosis can be key to enrolling patients in trials and giving them the best care possible.

Another aspect of giving patients the best care possible comes from multi-disciplinary teams (MDTs). Although several centres in the UK have MDTs set up to manage mesothelioma, in other places, patients may not have the benefit of MDTs. Consequently, these patients may not get onto the official radar straight away to learn about opportunities to engage with clinical trials.

William Cookson, Professor of Genomic Medicine at Imperial College London and Head of Respiratory Sciences for the College, is working with colleagues nationwide to address this challenge.

Professor Cookson says: “MDTs can tell new and existing patients about clinical trials and ask them where to go for extra information, in line with agreed protocols. Patients involved with clinical trials traditionally receive an optimal standard of care and we’re focused on ensuring that every mesothelioma patient has the opportunity to engage with the relevant clinical trials on offer.

“This is why we’re working with several different colleagues and agencies nationwide to explore a central way of getting people registered when first diagnosed. The development of this registry will enable us to focus on treatment for all registered mesothelioma patients and can also help to improve the detail of our research into treatments and hopefully, potential cures.”
Improving patient experience of mesothelioma diagnosis

Have you or a member of your family been diagnosed with mesothelioma in the last three to twelve months? Are you interested in sharing your experience of receiving the diagnosis?

RADIO Meso is a study, run by Sheffield University and funded by Mesothelioma UK, that aims to look at ways healthcare professionals could improve the diagnosis experience for patients.

What happens during the study?

The study will explore what it is like to receive a diagnosis of mesothelioma. Researchers will speak directly to patients and their carers, usually on the telephone, and ask questions about their experience of being told they have mesothelioma.

The researchers will look at what people think is done well and what could be improved.

Why is RADIO Meso being conducted?

We know that receiving a diagnosis of mesothelioma can be very distressing and challenging. The interviews will be used to make recommendations about how services can improve how they communicate a mesothelioma diagnosis.

Who can take part in RADIO Meso?

If you or someone in your family has recently received a diagnosis of mesothelioma (within the last three to twelve months), you may be able to take part in this research.

What do I do if I am interested in taking part?

If you are interested in taking part, please contact the Mesothelioma UK Helpline on 0800 169 2409 or email mesothelioma.uk@uhl-tr.nhs.uk. They will discuss the project in more detail and pass your details on to the researchers.

Mission to MARS 2

What is the MARS 2 study?

The study is assessing if it is feasible to recruit patients into a study of extended chemotherapy.

In the meantime we have successfully opened at a total of 15 sites around the UK to achieve the recruitment target of 112 patients. In August 2016 and has subsequently opened to recruitment at The University Hospital, Southam, Forth Valley Royal Hospital and The University Hospital, Wolverhampton Royal Gwent.

Where can I find out more information?

You can discuss it with the doctor who manages your mesothelioma. The MARS 2 website www.mars2.org.uk also contains information about the study.

Alternatively, you can contact Mesothelioma UK at mesothelioma.uk@uhl-tr.nhs.uk

Latest update on SYSTEMS-2 trial

Malignant Pleural Mesothelioma (MPM) is associated with a variety of symptoms including pain, which affects around 90% of patients. Pain is a particularly difficult symptom to control because it often doesn’t respond well to standard painkillers.

Radiotherapy has been used for a number of years to help control pain and is recognised by the British Thoracic Society as a component of standard care in the setting. Despite this, there is very little evidence to suggest how much radiotherapy should be given, what dose should be used at each treatment and how it should be delivered. There has also been very little work done to assess how effective it is.

The SYSTEMS study was the first prospective clinical trial of radiotherapy in MPM to use validated assessment tools to measure pain response. This multicentre, phase 1 study of 40 patients showed that a standard dose of palliative radiotherapy (30 Gray delivered in 5 treatments over 1 week) was associated with clinically meaningful improvements in pain for about one third of patients. Importantly, very few side effects were reported with this treatment.

The results from SYSTEMS have underpinned the development and launch of SYSTEMS-2 a randomised, phase II trial of radiotherapy for pain control. The aim of this trial is to establish whether a higher dose of radiotherapy (36 Gray in 6 treatments over 2 weeks) will be more effective for pain control than the standard dose, given in SYSTEMS. Whilst recent advances in radiotherapy technology have made it possible to safely give higher doses, we need to do a clinical trial to make sure that there is no increase in side effects.

Patients will be randomised either to receive the standard dose of radiotherapy over 5 days or the higher dose over 2 weeks. Pain scores will be measured using validated assessment tools, before the radiotherapy and 5 weeks after the treatment.

Palliative patients will also be reviewed at weeks 9 and 26, where, in addition to assessing pain, we will also look for any changes in tumour size (using a CT scan), side effects, overall survival and quality of life.

Where can I find out more information?

You can discuss it with the doctor who manages your mesothelioma. The MARS 2 website www.mars2.org.uk also contains information about the study.

Alternatively, you can contact Mesothelioma UK at mesothelioma.uk@uhl-tr.nhs.uk

A Tale of Two Families

By Laurie Kazan-Allen, Coordinator of the International Ban Asbestos Secretariat

Disability, disease and death follow in the wake of asbestos mining, processing, transportation and use. The connection between asbestos exposure and the occurrence of respiratory diseases and several forms of cancer has been well documented.

The World Health Organisation, the International Agency for Research on Cancer and other international bodies agree that asbestos is a class 1 carcinogen. Despite scores of countries prohibiting its use, however, two million tonnes of asbestos are still being consumed every year.

The tragic experiences of two families on different continents speaking different languages and living different realities illustrate the universality of the asbestos catastrophe. In Colombia, the use of asbestos is neither prohibited nor regulated with thousands of tonnes of asbestos being used every year. Amongst the biggest asbestos manufacturers in the country are the companies Eternit Colombiana S.A., Eternit Pacifico S.A., and Eternit Atlanticos S.A., the first of which manufactured asbestos-containing building products for decades in the town of Sabate, not far from the country’s capital.

With no available data on asbestos deaths and the economic and political power enjoyed by a much-valued local employer, asbestos diseases, until fairly recently, remained private tragedies. One by one, cases are now beginning to surface. In one family alone, three people have died from asbestos-related diseases. The first was Jaime Braivo – he died of asbestosis in 2012, his father Julio Braivo was next – he died of asbestosis cancer in 2012; in 2013, Julio’s son William died of mesothelioma, aged 52.

In another company town thousands of miles away from Sabate, four members of the same family died from mesothelioma: Pierre Jiménez-Sepúlveda, the father age 60 (1987), Franciso, the mother (2000) and two of her sons: Pierre- Paul age 44 (2003) and Stephane age 46 (2009). Pierre had worked at Eternit’s asbestos factory in the Belgian town of Kapelle-op-den-Bos, an area where, none of the others had done so – their exposures were strictly environmental. As part of the father’s contract he was obliged to live close to the factory; as a result, his family inhalled the deadly dust with every breath they took.

When Franciso became ill 11 years after her husband had died, she was determined to obtain justice for all those who had been poisoned by the company. Due to the hostility of the legal climate in Belgium and the power of the Eternit multinational which owned the notorious plant, it took ten years for her sons to get the case to court. In 2011, a judgment was handed down in their favour. Eternit appealed. However, on Tuesday March 28, 2017, an historic victory was achieved when the Brussels Court of Appeal upheld the ruling condemning the Belgian asbestos multinational for its failure to warn workers of the health hazards.

First trial planned from Victor Dahdaleh donation

Targeted and personalised therapy has transformed outcomes in many disease settings but unfortunately not in mesothelioma, so far.

In the Victor MesoLithium UK newsletter, we mentioned how the Victor Dahdaleh Foundation has donated £5 million for mesothelioma research, matching government funding that was announced earlier in 2016.

This support will fund groundbreaking research into mesothelioma at the University of Leicester, University Hospitals of Leicester NHS Trust and Papworth Hospital NHS Foundation Trust in Cambridge, to set up the National Mesothelioma Research Centre at Imperial College London. The three hospitals and hospitals will work to push forward new treatments for the disease.

As part of this funding, the first umbrella study for mesothelioma – a molecular-stratified clinical trial – is set to open in the second half of 2017. The trial will identify and select patients with genetic connections in their cancers for investigation and treatments. The aim of the trial is to create a potentially effective way of controlling the disease and improving outcomes for patients with relapsed mesothelioma.
The Mesothelioma UK team recently hosted a group of Japanese delegates, who came to learn more about what we do.

Members of the Japanese Ministry of the Environment (MoE), Environmental Restoration and Conservation Agency (ERCA) and Toyo Marine & Nichido Risk Consulting Co., Ltd, visited the team to research what Mesothelioma UK does and how we do it.

The MoE introduced the Act on Asbestos Health Damage Relief in 2006 to provide financial support to those with asbestos-related diseases and their families. ERCA is the organisation responsible for providing the support, such as medical care expenses, and the consulting company is researching how other countries support those with asbestos-related diseases.

Liz Darlison, Director of Services and Consultant Nurse said: “We were delighted to host the Japanese delegates. We were pleased to hear that they valued our opinion and were looking to us to offer them better practice advice on how to support people with diseases like mesothelioma. It’s testament to our strong reputation as a leading organisation in the care and treatment of asbestos-related disease patients.”

"It’s also pleasing to see a country actively trying to improve the support they offer. We hope that we gave them some useful ideas and information that they can take away and implement back in Japan."

Mesothelioma UK carried out a study of the benefits of local support groups and their results highlighted the importance of local groups that address the needs of patients, provide them with help when needed, offer companionship, and organise social activities, thereby ensuring that they can still enjoy themselves and not always feel like a patient.

The feedback from the study indicated that most people who attended support groups felt it had changed and added to the quality of their lives. They felt empowered to do more than they first thought they would be able to and through various activities, could take back control of their lives. Meeting informally meant that they could also address simple medical issues that enabled them to avoid hospital attendance. Although there are many support groups outside of London there has only been one group in London, operating out of Guy’s and St Thomas’ Hospital.

London Hazards Centre is a campaigning group and a registered charity established since 1984. They assist with trade union, tenants’ groups and community based campaigns on issues of health and safety in London. For several years London Hazards has campaigned on asbestos safety issues and has hosted the Action Mesothelioma Day in London on numerous occasions.

The lack of mesothelioma support groups in London and the south east has long been recognised by London Hazards Centre. We had discussed this with the Asbestos Victims Support Groups Forum some years ago, and have now established the London Asbestos Support Awareness Group (LASAG) to operate in London and across the South East.

London Asbestos Support Awareness Group
By Phil Lewis of The London Hazards Centre Trust

Mesothelioma UK Newsletter
Mesothelioma UK Newsletter

Awareness Group (LASAG) to operate in London. We had discussed this with London Hazards and were looking to us to offer them best practice advice on how to support people with diseases like mesothelioma. It’s testament to our strong reputation as a leading organisation in the care and treatment of asbestos-related diseases.

Our runners, cyclists and climbers have started their training and our cyclists have taken to their trusty bikes and it’s not over yet! The New Year kicked off with those going Dry in January, others have pledged to Skydive, hold Quiz Nights, Table Top Sales, Charity Raisings, Cake Sales, Coffee Mornings and much more and please do remember if you are doing something amazing, no matter how small or complicated, get in touch and let us know. We can help to support some of what it is and to send us your pictures and stories to celebrate your achievements. Your stories open people’s eyes. They are a powerful tool to help educate and get the message out there that asbestos is definitely not ok. It is still dangerous and can be found so in so many of the places we live and work. It can affect anyone, not just those that worked with it. So always be Asbestos Aware!

Our fabulous fundraisers have been busier than ever over the last few months raising funds and awareness for the charity as you all will see when you read what our volunteers have been up to. Their stories will make you cry, inspire and fill you all the same time, just like our Grown A Mo For Meso which was held in Essex recently. We sent you some fabulous photos sporting some great Mo’s which made it very difficult to judge but it just had to be done. Please go to our Mo’s for Meso page for the results. A huge thank you to all those who took part and help raise an amazing amount to support the charity.

In the next couple of months we have some wonderful things going on that you can get involved with. That’s if you haven’t already taken part in our ‘March a Mile for Meso in March’. This is a fun event and you can do it anywhere at anytime and it doesn’t have to be in March, just pick a month, and choose your lounge, garden, park or your local gym. Keapng it fit makes us all feel good especially after the long cold winter set in front of our TVs and probably over indulging too, so why not kick off spring with a spring in your step and take part in walking a gentle or robust mile for meso. If you are a patient this is a great way to help you get or stay fit and you don’t have to do it all in one go either, just give yourself a daily goal. The average for a mile is about 3,200 steps so an average of 74 steps a day and you will have reached your goal. Call us on our telephone/helpline number for your t-shirt and sponsor form and ask your family and friends to sponsor you.

‘Muffins for Meso in May’ last year was our very first event which was tied in with the World’s Biggest Coffee Morning and we had a fantastic response. You rallied your friends, neighbours and workmates together and baked your very best muffins to raise awareness and funds for Mesothelioma UK and I do hope that you will all be taking part again. We can give you a basic recipe card and you can add your very own unique flavour and if you have a recipe that you think we beat the rest, send in your pictures and recipes and we will feature them in our summer newsletter. Again we will be picking three lucky winners - ‘The Best Dressed Muffin’ ‘The Most Unusual Muffin’ and ‘The Tastiest Muffin Recipe’. We can provide you with badges, a poster, muffin cases and nappies, all delivered in our fabulous Forget Mesothelioma Not bags. Raising awareness and funds is vital so that we can fund mesothelioma research projects, we can support campaigns for better treatment and trials and with your help, we can make a difference to those living with mesothelioma.

Get your family, friends and colleagues to support whatever you do because you will be making a huge difference. To get your sponsor forms and party pack, please contact Jill Lemon on 0800 169 2409 or Jill.Lemon@lighthousecharities.org.uk

The most important thing is to have fun… I’d like to take this opportunity to wish you all a very happy Easter!

Jill Lemon
Fundraising & Marketing Manager
Gillian De Vito - Swimathon for Enrico

"Back in August 2015 close family and friends of myself and dear husband, Enrico, took part and swam in a Swimathon in his memory. Between us we covered an amazing 5,000 metres to raise awareness and in support of Mesothelioma UK. Afterwards feeling proud at what we had achieved and with very hungry appetites it was back to my house for pasta and meatballs for swimmers and supporters.

We had a wonderful time and a lot more people are now aware of mesothelioma, this terrible disease that took our dear Enrico from us at only 66 yrs of age in December 2014. We were able to raise £375.00 with the help of all our wonderful friends and I would like to thank everyone who took part, swimmers, supporters and of course those who donated."

Melanie Matthews & Sarah – Running 100 miles in January 2017

Mel’s Story - "In January 2016 my mum, Sandra Harrison, was diagnosed with mesothelioma. This was a huge shock to all of us as we had no idea when she had come into contact with it. We didn’t know how long Mum had only that it was an aggressive extremely terminal cancer. We had four short months. My mum was amazingly brave, she had every treatment that was offered to her, including chemotherapy and never complained about the pain she was in. Mum fought very hard, she had so much to live for, but unfortunately lost her battle in May, aged 62. There is a huge hole in our family now where Mum should be. Mum missed my wedding, my sister’s wedding, my brother’s wedding, my nieces and nephews’ birthdays. We take for granted things we will get to do in life. I could not do anything to stop Mum being taken from us, so I want to do something to help others in the same situation and make their proud. I am sure she would have loved it if I completed 100 miles (I can’t sprint and so running 100 miles in a month will definitely be a challenge). My mum would do anything for anyone and raising money to help people with this terminal illness and their families is something that she would think is important. Therefore I run in memory of you, Mum. I run to run round the world it would bring you back to us xx"

Sarah’s Story - "So I said “Mum, you know you want to do something to raise money for charity for your mum?” She said “yes” so I said “let’s run a 100 miles in January!” So here we are...Mum’s mum was diagnosed with this awful cancer, which took her too soon. When we met and Mum told me what had happened it made me feel so sad and I knew he’d be there too but I’m sure he would be there too. I think he’d be there too. I think he’d be there too. I think he’d be there too. We still missed him so much. He was a real family man. He loved hockey so much. When Mum died he left behind his sister Pauline and his young nephew Harry and niece Rosie as well as his mum, dad and siblings.

I always knew asbestos was dangerous but wasn’t aware of the disease it could cause. When Mum was diagnosed I was determined to raise as much awareness and money as possible to try and help other families in future. I decided to challenge myself and in April 2016 I signed up to take part in the great Scottich run half marathon the following October. I also recruited my daughter, niece and nephew to do the junior run and my best friend Mum signed up for the 10k. Training was hard especially after Mum passing away but I always believed that Mum could do anything with what he did then I could run 13.1 miles."

On 1st October the kids did their junior run, all three of them did absolutely well and we were all so proud as we cheered them on!

Next day it was the turn of Mum and I, we both completed our runs and pushed ourselves out of our comfort zones. Finishing the marathon with all my friends and family cheered in the final meters was emotional and reminded me of exactly why I was doing it. I had hoped that when I signed up Mum would be there too but I’m sure he was looking down on us all.

In total we have raised an amazing £2,230.00 and we send a big thank you to all our wonderful supporters.”

Beuch Becte

Sue has organised many fundraising and raising awareness events throughout 2016/17 in memory of her beloved husband, Kurt. These events included a recent Rift for a Rotterdam Hot Spitis Football Club day out which raised an amazing £370.00. This brings the overall total funds raised so far to an outstanding £20,404.83 which is just amazing. Sue would like to thank everyone who participated and took part in various events and those that supported her raising awareness and much needed funds for Mesothelioma UK. She is overwhelmfed for the admiration and support she received from family, friends and colleagues in tribute of her gracious husband Kurt who was a wonderful husband, father, son, brother, and dear friend.

Janine Armstrong

“In February 2016 my brother in law Matt was diagnosed with mesothelioma at 40 years old, he had worked around asbestos so it came as a real shock to the family. On 1st June 2016 Matt passed away just 3 months after diagnosis and two weeks after his 41st birthday. Matt worked as a technical writer and was a real family man. He loved his family so much. When Matt died he left behind my sister Pauline and my young nephew Harry and niece Rosie as well as his mum, dad and siblings.

I always knew asbestos was dangerous but wasn’t aware of the diseases it could cause. When Matt was diagnosed I was determined to raise as much awareness and money as possible to try and help other families in future. I decided to challenge myself and in April 2016 I signed up to take part in the great Scottich run half marathon the following October. I also recruited my daughter, niece and nephew to do the junior run and my best friend Mum signed up for the 10k. Training was hard especially after Matt passing away but I always believed that Mum could do anything with what he did then I could run 13.1 miles.

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In total we have raised an amazing £407.52 Dannii x”

Danni Kennedy – Cycling round Kielder for my dear Dad Kelvin

“It had been four years since I had last been to Kielder, the last time was with my dad, biking of course. This time was different, not only because he was not there with me but because I am four stone heavier and don’t have the fit body I used too. The rain was awful. Heavy and cold, typical British weather despite it being the middle of August the 20th to be exact.

The next day which of course was forecast to be glorious, my brother-in-law Dave and myself set off around twelve. We went around the route clockwise, the start point being Leafield. Every small uphill climb was a challenge and every steep uphill climb was an ordinary, the muscles in my legs literally burning. But despite all of the hardships we still managed to do the full lake (approx 256) in around 5-6 and a half hours.

Due to Dave doing it with me and my cousin Matthew Kennedy whom I am so pleased to see there too. Thank you to all the donators, all of my supporting family, my boyfriend John (who had to deal with me moaning afterwards) and my friends. XOXOX Also Thankis to Scott Kincaid for loaning me some basic equipment. “Hugs”. We have raised nearly double what I intended £407.52 Dannii x”

Jennifer and Team Batts – Our year of challenges

“Our family of 4 will be completing a year of challenges throughout 2016 to raise money for Mesothelioma UK in memory of my dear father-in-law, Michael Battersby.”

Challenges

21st Feb 2016

Skateboard Half Marathon

Adam & Jacqui

10th April 2016

Manchester Half Marathon

Jackie

14th May 2016

Lincoln Colour Dash

The Whole family!!

18th June 2016

Lincoln Race for Life 10k

Adam

7th Aug 2016

Nantes Bourde Ironman

York 10k

16th October 2016

Birmingham Half Marathon

Jackie

This lovely family has raised an amazing £1, 223.631

Julie Mclean – Tatton 10k on Sunday 20th November 2016

“My gorgeous husband was diagnosed with this devastating cancer last year at the age of just 57 and our lives have been turned upside down. We had never heard of it let alone pronounce it and it was a huge shock. It is very difficult to diagnose. Very little money seems to be available for research - it is a relatively rare cancer which is very much overlooked - and this wonderful charity needs all the help they can get. Money that I have raised will go towards clinical research and helps towards providing specialist nursing care throughout the country; something we have personally found to be invaluable and a huge support at this difficult time. Well I did it, I finally ran all the way and loved every minute it was actually very emotional for me - thank you so much all for your support I am truly grateful for every single penny. Love you all xxx”

£753.75

Carolyn McFarlane – Miles for Meso

Carolyn braved the elements and ran a Mile for Meso everyday during January which is just fabulous. She raised a wonderful £314.54

Amy Purse’s Big Shear

“Hi, my name is Amy, I am almost 15 and I’ve had my hair cut off, 60cm to be exact! Because I have so much hair to spare I thought it would be brilliant to donate it to The Little Princess Trust who make wigs for children who have suffered hair loss due to having cancer treatment, for example costs between £350 and £500 to make one wig so I would like to help pay for them to turn my hair into a wig. I am donating all the funds I raise to Mesothelioma UK and Longfield House (Cotswood Care Hospital) to say thank you for the support they gave my lovely Bampy through his illness, giving him and our family so much care in his final weeks. This is my first big fundraiser and I am proud to say I have raised £706.25 in memory of Grandfather, Graham Purse.”

St Mary’s Boys - Oliver, Jake, Nat, Aaron, Hameen & Esa

St Mary’s Boys ran together as a team to support their friend Oliver and his family. Oliver’s lovely Grandad Ted, recently passed away with mesothelioma. Ted had been involved in the boys’ lives often giving a helping hand and taking Oliver along with some of his friends to various activities. The boys wanted to support Oliver and his family and they also wanted the money to go to a good cause. Well the boys have raised an amazing £586.54 and they are really grateful for all donations received.

£586.54
Grow a Mo for Meso

Finally we have our pictures for Grow a Mo for Meso in November and we would like to thank everyone who took part in this wonderful event and raised awareness and funds.

Our three lucky winners will each receive a £25.00 On the High Street Voucher and a certificate for their wonderful efforts, and they are:

1. The Longest ‘Captain Birdseye’ Mo – Joe from the Anglia Asbestos Support Team

2. The Bushiest ‘YMCA’ looking Mo – Matthew Watkins from Laing O’Rourke

3. The Most Original ‘Miniature Schnauzer’ Mo - Dr Van Leuven

The Anglia Asbestos Disease Support Group which includes Brentwood, Norwich and Bury St Edmunds along with their wonderful supporters Pinney Talfourd and Ashtons Legal took part in the Grow a Mo for Meso campaign, donations came from across the region from Kings Lynn in the north and Southend on Sea in Essex and their fundraising efforts have raised an amazing £2,355.75.

The Asbestos Claims Team at Royds Withy King Lawyers took part in Grow a Mo for Meso and wore a mo in the office in November and raised £148.32.

Jane Halton & Family raised £165.60 – Tim & Andy took part in Movember in support of ‘Grow a Mo For Meso’ and the family raised the rest by fundraising.

“The Anglia Asbestos Disease Support Group put forward Consultant Dr Van Leuven, and this is what she had to say...”

“Always known for doing things in a slightly different way! Dr Van Leuven returned from holiday with a monstrous growth on his top lip. We raised money to get rid of the thing and fortunately raised £213.00 which he agreed was enough to shave which created a huge relief in the department as he was beginning to look a bit like a miniature schnauzer and was worryingly beginning to be rather proud of it. December is here, money has been received and we can breathe a sigh of relief that the growth has gone.”

“Geraint, Matt & Dave from Laing O’Rourke who are currently working on the Sobell Redevelopment Project in Aberdare Wales have raised funds by growing their Mo’s for Meso, and this is what they had to say...”

“We wanted to raise money for a disease that effects a number of people who work closely with us in the asbestos industry. Through Mesothelioma UK we all took part in Grow a Mo for Meso, by growing a moustache through the month of November. They raised a fantastic £582.30 on site through their fundraising efforts – Grow a Mo, bacon and coffee mornings and the selling of pin badges and bands. Well done lads we really do appreciate your support.

“On Thursday 3rd November the Specialist Asbestos Team at Novum Law donned moustaches and held a “Wear a Mo for Meso” fundraising day. There was a raffle, some games and a delicious array of home made cakes for sale, raising a total of £759.17p for this amazing cause!”

Jane Halton & Family raised £165.60 – Tim & Andy took part in Movember in support of ‘Grow a Mo For Meso’ and the family raised the rest by fundraising.

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Jane Halton & Family raised £165.60 – Tim & Andy took part in Movember in support of ‘Grow a Mo For Meso’ and the family raised the rest by fundraising.
The girls raised £3,900.00 in support of their mum Susie.

Woodzy’s Charity Night on 26th October 2016 in memory of his dear mother, Margaret Edgington.

Michele Ekhosu – Wigglesworth Half Marathon on Sunday 13th September 2015 in memory of her dear mum, Marie Laporte, raised £700.

Kathy Warnor – Bake to the Brink on Saturday 16th July 2016 in memory of her dear sister, Shane, raised £678.12.


Mrs A Alcott – Collection Tub at the Vine Public House in Mickleover raised £27.

Sarah & Colin Parson – Walk for the Cure on 18th September 2016 in memory of David Richardson raised £2,601.25 which includes £1,112.40 in support of a staff member’s father.

Lyn Halls – Charity Christmas present in memory of her dear brother Roy Hall, raised £300.

Mrs T Allott – Annual Innings Meeting raised £1,000.00.

Lesley White – Collection Box at Freemasons Hall on 18th September 2016 in memory of her dear husband, Roy Hall, raised £265.00.

Alan Ebbens – Annual Innings Meeting raised £1,038.00.

John Finch Mason – Solicitors held Dress for Success Fashion Show on 2nd October 2016 raised £912.44.

Sue Brier & organiser Margaret Hill – Held a Charity Evening Quiz Night on 12th November 2016 in memory of her husband Jan Frier, raised £1,292.00.

Carole Willis – Sold handmade items by substituting Adults & Raffle held at The Enterprise in Walsall raised £205.00.

Sara Turner – Winshill Ladies Group raised £460.00.

Sara Turner – Winshill Ladies Group raised £460.00.

Mrs & Roper held a small Quiz Night on Saturday 11th September 2016 raised £300.00.
Chloe Sword - Bournemouth Full Marathon Festival Sunday 2nd October 2016

“I ran my first full marathon to raise money for the work that Mesothelioma UK do and to raise awareness of this horrible disease. My father in law sadly passed away in 2014 after fighting for 3 years with mesothelioma. He held on to see his last granddaughter, my daughter Lottie and got to spend the 1st year of her life with her until he became too poorly. He was a brave man until the end and leaves behind his wife, 2 sons and 3 grandchildren who miss him dearly. I trained hard in the precious time I have being a mum to my 4 children because I wanted to run all the way and hoped to complete within a reasonably good time, I ran with good friends and we supported each other until the end.” Chloe raised a fantastic £705.25.

Louise Walker & Andrew Parkin - Tough Mudder

Louise and Andrew took part in the South West Tough Mudder Challenge on Sunday 21st August 2016. They did this challenge to test themselves and to also raise money to a charity close to the Walker’s hearts. Stephen Walker sadly lost his battle to mesothelioma and they wanted to raise some money to help fund the work the charity does, they completed their challenge and they raised a huge £726.75.

This is what Anna Walker had to say…
“Thank you for all that have donated on and offline, the support was brilliant thank you. Both Louise and Andrew completed the whole course, very well done to them both. Dad would have been very proud.”

Snowden, Crosby & Sullivan Families – Lynda, Julie, Jason, Tracy, Joel, Georgia, Hannah, Paull, Tom, Jamie and Louis

“In January 2015 our lovely Mum and Grandma died from a dreadful disease that we knew nothing about until she was diagnosed 7 months earlier. Mesothelioma is a terminal cancer caused by the inhalation of asbestos fibres, in Mum’s case it caused cancer of the lining of her lungs, despite her never working with asbestos this shows what a danger this substance can be and awareness needs to be raised of this dreadful disease.

For those of you that knew our Mum she was very hardworking, extremely active and loved life. She loved nothing more than being outside with her Grandchildren. During the 7 months following diagnosis she was in and out of hospital and on one occasion had 6 litres of fluid drained from one lung. There are very few options for treatment available currently because of the limited amount of funded research that has been undertaken into the disease. This is a cruel disease and we want to try and help other families by raising money to research treatments and ultimately a cure. As a family we all undertook individual and family challenges which included:"

Lincoln 10K - Julie, Jason, Tracy and Joel
5k run - Julie, Tracy, Georgia and Hannah
5k pretty muddy run - Lynda and Julie - 1st October 2016
Triathlon - Lynda, Julie and Jason - Lincoln Half Marathon - Tracy and Jason
Hadrians Wall, 80 mile walk - Paull and Tom
Ben Nevis, Scafell Pike and Snowden climbs - Lynda, Jamie, Joel, Louis, Paul, Tracy, Tom, Georgia, Julie, Jason and Hannah
100 mile bike ride - Jamie - September 2016
Swim - Louis and Georgia - 16th October 2016

They raised an amazing £2,892.78 in memory of mum and Grandma Jean Snowden.