Dear Mesothelioma UK Supporters

This edition is packed with updates and information about fundraising, service developments, clinical trials, events and activities all dedicated to mesothelioma.

It is increasingly hard to keep pace with everything that is happening which is beyond wonderful. Having worked exclusively in mesothelioma for over 13 years, I confess that I once dreamt of this level of interest but never thought that it would happen to this extent.

It probably feels of little consolation to those of you living with mesothelioma but honestly, it is this level of activity and interest that will see us with more treatment options and better outcomes.

Professor Cookson from the Imperial College National Mesothelioma Centre, during one of the first meetings I had with him, referred to mesothelioma as ‘a problem to be solved’. His words fill me with hope that I want to pass on to you all too; there is never one solution or answer to a problem but hopefully, with so much happening, we are now on course to see improvements that are long overdue.

July brings Action Mesothelioma Day. Please look up where the events are taking place and show your support by attending if you can. We have also booked this year’s Mesothelioma UK Patient and Carer Day on Friday 13 October in Teddington, Middlesex. Details will be shared over the summer.

A huge thank you to all of our supporters, we couldn’t do anything without you. No matter how big or small your contribution, rest assured that Mesothelioma UK works hard to ensure we use it wisely and put funding, support and information into the heart of our wonderful NHS to reach those affected by mesothelioma.

Don’t forget that we are always keen to hear your ideas and comments, whether you are a patient, family member, doctor, nurse or support group organiser, we are here to help and support you so please let us know what you think.

So, UK Meso community, let’s hope we have a summer packed with long days and sunshine, and more importantly, some good news for mesothelioma.

Liz Darlison

Action Mesothelioma Day will be commemorated with events taking place across the country. See Page 6 of this newsletter and www.mesothelioma.uk.com for more details.
National mesothelioma audit

By Susan Harden, Consultant Clinical Oncologist and Co-Clinical Lead for the National Lung Cancer Audit

Since the successful launch of the second Mesothelioma Audit report (data from 2014) at the British Thoracic Society Winter meeting in December 2016, the team at the National Lung Cancer Audit have been working with Mesothelioma UK to plan the next steps for the third audit, due to report in 2018.

We were delighted that the recent report showed an increase in overall survival and the use of systemic treatments, compared to the first report and hope that multi-disciplinary teams across the country will be able to use the report to drive change and reduce variation.

At the British Thoracic Oncology Group (BTOG) and Meso UK Essential Update stay in March 2017, after presenting a summary of the audit, several interesting suggestions were made which we hope to include within the next audit. In particular, we will have access to the National Radiotherapy Dataset (RTDS) and Systemic Anti-Cancer Therapy (SACT) dataset that will help us report in more detail on the active oncology treatments received by mesothelioma patients across England.

As the next audit will include three years of data (2014-2016), we also hope to use registry data from the National Cancer Registration and Analysis Service to include a focus on the rarer pleural mesothelioma cases in addition to our reporting on pleural mesothelioma.

Hypoxia investigations

By Professor Luciano Multi, Professor in Cancer Research, University of Salford

An important part of our current research on mesothelioma is funded by Mesothelioma UK and awarded through the British Lung Foundation. It investigates the role of oxygen deficiency (hypoxia) and microRNAs in mesothelioma development.

MicroRNAs are factors that contribute towards the control of gene expression and some of these, such as microRNA-210 (miR-210), are regulated by hypoxia.

Our project is currently in its early stages and is focusing on completing the preliminary data on the role of miR-210. In collaboration with a colleague at the University of Sydney (Dr Glen Reid) we have confirmed that miR-210 levels increase with hypoxia, and that reduction of miR-210 using specific inhibitors increases the response of mesothelioma cells to drug treatment.

What is Radio Meso?

Mesothelioma UK is funding a study (Radio Meso), looking at patients’ experiences of receiving their mesothelioma diagnosis. The study is being carried out by researchers at the University of Sheffield and aims to improve the experience for patients and their families.

Progress with Radio Meso

The first stage of the study is going well with patients and their families being interviewed about their experience of being given the diagnosis.

Group interviews with specialist nurses and mesothelioma healthcare professionals will take place in the summer, to hear their views on communicating a diagnosis.

Focus groups will take place in the autumn and winter, and exercise will develop recommendations for best practice to be published as a ‘Mesothelioma UK Good Practice Guidelines’.

Are you interested in taking part in the research?

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

If you are interested in sharing your experience of receiving your diagnosis, please contact the Mesothelioma UK Helpline on 0800 169 2409 or email mesothelioma.uk@btinternet.uk
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Current management of Peritoneal Mesothelioma in the UK

By Akash M. Mehta, senior clinical fellow Peritoneal Malignancy Institute Basingstoke and North Hampshire Hospital

Peritoneal malignancies are tumours that arise and spread inside the abdominal (peritoneal) cavity. They include peritoneal mesothelioma, which is a malignancy arising from the peritoneum itself, and metastatic peritoneal malignancies such as pseudomyxoma peritonei (PMP), which arises from the appendix, and peritoneal metastases of colorectal, ovarian, gastric and pancreatic cancers.

The treatment for peritoneal malignancies is aimed at removal of all macroscopic disease, termed cytoreductive surgery (CRS). This is achieved by a combination of peritonectomies (removal of the peritoneal lining of the abdomen) and cytoreductive chemotherapy. CRS and HIPEC is performed in a small subset of patients for either of two goals: to obtain survival benefit in patients in whom all macroscopic disease can be removed (complete cytoreduction); or to achieve symptom relief (including alleviation of ascites and bowel obstruction) by performing a major tumour debulking.

Basingstoke and North Hampshire Hospital are working closely with The Christie Hospital, Good Hope Hospital and Mater Misericordiae Hospital in Dublin, and the National Peritoneal Malignancy Multi-Disciplinary Team (NPMMDT), bringing together leading clinical specialists to discuss every referred patient focusing on their presentation, diagnosis and treatment options and providing recommendations for their further diagnosis and treatment.

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 future commissioning decisions.

The NPMMDT has held 12 meetings since March 2016 and has discussed 66 patients. The NPMMDT has recommended 5 patients for surgery, 6 potentially for surgery pending further investigations, and others for chemotherapy in the first instance, with possible surgery as a subsequent treatment option.

At Basingstoke and North Hampshire Hospital, 76 patients have undergone CRS and HIPEC for peritoneal mesothelioma since 1998. 39 of these had low-grade mesothelioma (either epithelioid or well-differentiated papillary mesothelioma) and 37 had high-grade mesothelioma (including epithelioid and biphasic mesothelioma). In 52 patients (46%), a complete cytoreduction was achieved and 20 (26%) underwent a major tumour debulking.

Overall, 75% of patients were alive 3 years after surgery, with 67% still alive 5 years after surgery. These survival results depend heavily on the type of mesothelioma. In patients with low-grade mesothelioma, nearly all patients (86%) were still alive 5 years after surgery.

In patients with epithelioid disease, 52% were alive after 3 years and 34% after 5 years. Patients with biphasic mesothelioma had the worst outcomes, with 38% alive after 3 years and 19% alive after 5 years.

Naturally, the ability to remove all disease had an impact on survival. After complete cytoreduction, 88% of patients were alive after 3 years and 79% after 5 years; in a major tumour debulking 48% were alive after 3 years and 40% after 5 years.

The Basingstoke experience has shown that with good patient selection (based on various factors including the type of mesothelioma), complete CRS and HIPEC can achieve long-term survival in patients with peritoneal mesothelioma. The results have contributed to increasing numbers of referrals specifically to the NPMMDT; we anticipate making treatment recommendations for over 100 patients a year initially and crucially, to collate the outcomes of any treatment provided in a national peritoneal mesothelioma registry.

Patients can get referred to the NPMMDT by their local team, who can send a letter to any of the consultants at the Peritoneal Malignancy Institute Basingstoke.

Cordotomy service launch

Lorraine Creech, Clinical Nurse Specialist and Team Leader, recently attended the launch of a new pain management service...

It was a privilege to attend the Interventional Cordotomy Service Launch on the 15 March 2017 at the Beatson West of Scotland Cancer Centre – a service for which Mesothelioma UK has provided funding for equipment.

The launch presentations were opened by Dr Don Doherty, Clinical Director and Acting Chief of Medicine who chaired the meeting, Dr Alison Mitchell, Clinical Lead for Interventional Cancer Pain Service outlined the commitment of the West of Scotland Interventional Cancer Pain Team to make these developments happen. Dr Mitchell also explained the background to referral and patient assessment process.

In July 2015, NHS England concluded there was insufficient evidence for the recommendations for over 100 patients referred to Basingstoke are considered unsuitable for surgery and will be referred back to their local team for systemic chemotherapy.

The launch means that the service is now open for referral for:

- patients with unilateral cancer-related pain below the neck, above the knees, chest, wall or arm
- pain which is uncontrolled or likely to become so
- intolerable side effects of analgesia
- life expectancy of probably less than 2 years

This is a remarkable development for patients with peritoneal mesothelioma where their pain has been so difficult to control.

The network’s activity will be overseen by a steering group including representatives from the University of Leicester and University Hospitals of Leicester NHS Trust, and Papworth Hospital NHS Foundation Trust.

The British Lung Foundation (BLF) is pleased to announce the first instalment of grant awards, totalling more than £500,000, to two vital research projects at the University of Leicester and University Hospitals of Leicester NHS Trust, and Papworth Hospital NHS Foundation Trust.

The British Lung Foundation, who worked closely with Mr Victor Dahdaleh to secure the generous £2.5 million donation for mesothelioma research, will be able to support the two high-quality research projects for four years. The funding supports MesobanK at Papworth Hospital and a molecular-stratified clinical trial at University of Leicester and University Hospitals of Leicester NHS Trust (both of which were featured in the Spring issue of the newsletter).

As a condition of receiving the donation from the Victor Dahdaleh Foundation, the BLF has agreed to set up a national mesothelioma research network. The aim of the network is to drive research progress faster than ever before by connecting researchers. It will encourage sharing of information, knowledge and resources among research groups, reduce any unnecessary duplication of research and encourage researchers to work together to tackle big research challenges.

The team is working closely with Mr Victor Dahdaleh to secure the generous £2.5 million donation for mesothelioma research, which will allow the network to be developed and delivered.

Patients with mesothelioma are best scanned in the portovenous phase from the aorta to the groin. This is the best phase for pleural enhancement. The patients are scanned from the aorta to the groin contrasting (we use Nioam 300) with 70-second delay. This is ideal for the thoracic and abdominal extension of the disease.

I think it would be useful to standardise the protocol to the pleural protocol if suspecting/already diagnosed mesothelioma in cases referred to the regional MDT.

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More than £500,000 awarded to two mesothelioma research projects

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The network’s activity will be overseen by a steering group including representatives from the University of Leicester and University Hospitals of Leicester NHS Trust, Papworth Hospital NHS Foundation Trust, the National Mesothelioma Research Centre at Imperial College London, and patient support groups. After two productive meetings of the Steering Group, the British Lung Foundation is pushing forward planning the network activity. This includes taking a number of researchers to find out what they need from a research network.

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Optimal CT protocol for mesothelioma scanning

By Amrita Bajaj, Consultant Radiologist, Glenfield Hospital, University Hospitals of Leicester

Mesothelioma is almost always staged with an initial CT. The protocols however can vary depending on the reason for initial referral.

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Action Mesothelioma Day 2017

Action Mesothelioma Day is an annual day on which events take place across the country to raise awareness and pay tribute to all those people affected by mesothelioma. Here are some of the events happening to mark the day. We hope that you can take part in one near you.

Leicester - Mesothelioma UK
2pm, Friday 7 July
Leicester Cathedral, Peacock Lane, Leicester, LE1 1DE
A Service of Reflection and Hope will be followed by a symbolic Dove Release and refreshments will be served in the cathedral.

Paper doves are available for your messages to hang on the tree remembrance and will also be available on the day. If you wish to add your loved one’s name to the scroll of remembrance that will be shown during the Reflection Service, please contact the Mesothelioma UK team on 0800 169 2409 or email mesothelioma.uk@uhl.tums.uk

Portsmouth - HASAG
12pm, Friday 30 June
The Inn Lodge, Burrfields Road, Portsmouth, PO3 5HH
A dove balloon release, raffle, tombola and buffet. Confirmed guest speakers are Hisham Shalhoub, Retired Occupational Physician, added:
• The event will take place at the Provan’s Lordship’s Gardens. Thereafter, all are invited for lunch at St Mungo’s Hall. We have chosen to host our memorial to commemorate all those who have died and continue to die from asbestos related conditions.

Manchester - Greater Manchester Mesothelioma Support Group
12.30pm, Friday 7 July
Sackville Gardens, Sackville Street, Manchester M1 3WA
Release of sponsored doves followed by public meeting (1pm-2pm) hosted by Professor Sir Anthony Newman-Taylor, Chair of the National Mesothelioma Research Centre at the Mechanics Institute, 103 Princess Street, Manchester, M1 6DD.
For more information, call 0161 636 7555, email asbestos.gman@gmail.com or visit www.asbestossupportgman.co.uk

Cambridgeshire - Papworth Mesothelioma Social Group
1pm, Friday 7 July
Hemingford Abbotts Village Hall, Hemingford Abbots, Cambs, PE8 9AH
A meeting of the group to celebrate the lives of those we love and those we have lost over the past year, and also to look forward to the future. Strawberry tea will be followed by the release of doves.

Leeds - The June Hancock Mesothelioma Research Fund and Mesothelioma UK
11am, Friday 7 July
Hargreaves Building, Chapel Street, Liverpool L1 9JD
Public meeting with guest speaker, Dr Chris Warburton. 11.15am followed by a sponsored dove release at 12 noon at Exchange Flags to the rear of Liverpool Town Hall, assisted by local school children.

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Please contact Kate Slaven on 01482 830541 x4889, or kateslavenlincs@hotmail.com for more information.

Shffield - South Yorkshire Asbestos Victims Support Group (SARAG)
Starting at 11am, Friday 7 July
Sheffield Cathedral, Church Street, Sheffield, S1 4HA
Guesses and invited speakers include Sheffield Lord Mayor, Helenus Stanley, Mesothelioma Lung Cancer Nurse Specialist, MPh, Trade Union leaders, and June Hancock Mesothelioma Research Fund.

The event will start in Cathedral Square to read out all the names of those killed by mesothelioma, asbestos cancers and diseases in South Yorkshire & North Nottinghamshire, followed by speakers, buffet lunch and refreshments in the Domini Hall at the Cathedral.

We hope to conclude with a candle lighting remembrance and performance by Sheffield Socialist Choir. Donations for this event will go to mesothelioma research.

For further details please contact SARAG on 01790 360 672.

Menserise: Men's-erie: Asbestos Victims Support Group
11am, Friday 7 July
Hargreaves Building, Chapel Street, Liverpool L1 9JD
Public meeting with guest speaker, Dr Chris Warburton. 11.15am followed by a sponsored dove release at 12 noon at Exchange Flags to the rear of Liverpool Town Hall, assisted by local school children.

Study aims to reduce the need for diagnostic surgery

A Pat Stone Meso Support/Mesothelioma UK grant has been awarded to fund a new study that aims to reduce the need for diagnostic surgery.

“We’re delighted to be working with Pat Stone Meso Support and the National Lung Cancer Forum for Nurses (NLCFN) to offer this grant for such an innovative study. We’re excited to hear about the results of the study which we hope will inform current diagnostic processes and perhaps lessen the need for surgery for people with suspected mesothelioma.”

Graham Pound from Pat Stone Meso Support said: “Pat Stone Meso Support is extremely proud to be associated with this opportunity which has the potential to further the understanding and care of sufferers of this cancer which continues to take the lives of substantially more people than are killed on our roads each year.”

This study is a prospective single blinded study of patients undergoing diagnostic surgery for suspected mesothelioma. It will be conducted in a regional specialist thoracic surgical unit serving the West Midlands.

Patients attending the preoperative assessment b u ffet. Cent grade patients who are undergoing diagnostic pleural biopsy will be invited to join the the study by a suitably qualified member of the thoracic surgery team. Written informed consent will be received after the patient has had time to consider the study. After giving consent patients have the SLP test prior to surgery. Surgery will proceed as planned and involvement in the study will not change or delay treatments.

Integrating SLP into future clinical practice to diagnose mesothelioma could:
• Improve the diagnostic process for patients with possible mesothelioma and reduce the need for hospital admission for invasive investigations and reduce distress associated with surgery
• Reduce the length of time patients have to wait for a diagnosis, which can be a very stressful period
• Offer an alternative for patients who are not well enough to have surgery so that they can receive a more confident diagnosis for their pleural disease; this could help provide evidence for civil claims and gain these patients financial support

Emerging results will be presented at the NLCFN conference in November 2018.

Trustees agreement to fund five new CNSs

Mesothelioma UK Trustees have recently delivered some good news by signing off plans to recruit five new Clinical Nurse Specialists across the country.

The posts will be in place by November 2017 and will be in Southampton, Kent, Liverpool and two in London to boost our existing team of CNSs.

Mesothelioma UK is tremendously grateful to all of those who support us. Without your efforts we could not support these much needed posts. We are particularly grateful to Pat Stone Meso Support which has funded one of the posts for an initial three years.

We’ll share more on the launch of each post as they are recruited.
Specialist service for military personnel

Mesothelioma UK will be offering a new service to help people just like Kath and Steve Fiander. The charity has successfully secured a Government grant to establish a UK-wide service for military personnel and veterans who have been affected by mesothelioma.

The funding comes from fines levied on the banking industry for manipulating the Libor rate (the London Inter-bank lending rate). Proceeds from LIBOR fines are to be used to support good causes, in particular military and emergency services charities.

The benefit and compensation claims process is particularly complex for military personnel as the law protects the Ministry of Defence (MoD) from being sued for compensation for asbestos-related disease before 1987.

Our new service will provide a specialist nurse and a finance and benefits advisor who will deal specifically with military personnel and veterans. It will also raise awareness of the disease amongst military personnel and veterans, and signpost available support.

Liz Darlison, Mesothelioma UK Director of Services and Consultant Nurse, commented: “We felt it was important to help military personnel and veterans with mesothelioma as their compensation process is uniquely complex and needs specialist advice and support.”

“We will establish a comprehensive service of information, advice and support – all focused specifically on military personnel, both serving and retired. We will work with military charities, the Department for Work and Pensions and the Citizens’ Advice Bureau to support military personnel and their families.”

“We will be able to support and advise families like the Fianders who were affected by mesothelioma due to asbestos exposure while Steve was in the RAF.”

HASAG makes a difference

In the previous Mesothelioma UK newsletter, we reported that the HASAG Asbestos Disease Support Group for sufferers in the south of England had generously donated £200,000 to Mesothelioma UK.

HASAG was started by Lynne Squibb and her sister, Diane, in 2006 after their father, Dave sadly passed away after contracting mesothelioma. HASAG covers the south east of England, London boroughs and the Home Counties.

HASAG’s mission was to raise money from coffee mornings and other fundraising activities to support new research, nurse recruitment, funding visas to go to educational events and conferences, and much more. The majority of HASAG’s work is supporting patients at home to receive government payments, compensation and ongoing support. They visit every patient at home to offer any advice and help that they need. HASAG works closely with Lung CANS among the region to prevent isolation during their illness. Its approach is holistic, ensuring that family are supported as well as the patient. HASAG received coffee mornings and funds others, enabling patients to meet one another and share their experiences.

HASAG is also part of the Asbestos Victims Support Groups Forum which is an umbrella organisation bringing together all the bona fide groups in the UK to lobby the government for better treatment, diagnosis, trials and access to compensation/benefits. The Forum works tirelessly to raise awareness of all asbestos diseases and promote the dangers that still exist.

Since its formation, HASAG has raised over £325,000 for Mick Knighton Mesothelioma Research Fund, June Hancock Mesothelioma Research Fund and Mesothelioma UK.

HASAG has supported Mesothelioma UK for over three years with fundraising now passing £355,000. 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, Cambridge, Oxford and Plymouth.

Lynne Squibb adds: “It’s vital that patients feel completely supported during their diagnosis and treatment. HASAG funds, we can help mesothelioma nurses to ensure that they receive and communicate the latest information on clinical trials, as well as signposting patients to any other contacts such as law firms or therapists. We’d like to support Mesothelioma UK and hope that our contribution is helping to make a difference to the lives of meso patients.”

Mavis Nye Foundation officially registered

Mavis Nye was diagnosed with mesothelioma in 2009 and given just three short months to live. Thankfully, Mavis proved the doctors wrong and after years of campaigning and awareness raising, has just set up her own charity, the Mavis Nye Foundation.

After her diagnosis, Mavis used social media to reach out to others with mesothelioma. Mavis, researched mesothelioma extensively and shared her knowledge with the other ‘mesowomen’ as they called themselves.

Mavis set up Facebook groups for patients and carers, and supported people online and over the phone. Helping others, despite her own condition, became Mavis’ focus.

Her treatment continued for four years yet the side effects of chemotherapy did not deter her desire to offer advice and help. She published two books, gained several thousand followers, and was now known amongst the mesothelioma communities in places like America, Australia, India, France, Canada and Italy.

After the chemo treatment, Mavis received the devastating news that her cancer was growing again, that chemo was no longer an option and that there was no more treatment available for her.

But her time over those four years of treatment had been well spent. She had met many inspirational people and had been invited to speak in the House of Commons among other places. It was during one of these talks that she met Professor Dean Fennell. He mentioned that the Royal Marsden were holding trials and that one may be suitable for Mavis.

Eventually she was offered a place on an immunotherapy trial and after two years was told that while her tumours were still there, there was no active mesothelioma in them. An astounding result that shows the importance of research into new trials and treatments. It also shows the importance of Mavis’ fighting spirit and determination to beat mesothelioma. A determination she wants to pass onto others.

A friend suggested that she set up her own charity and with his help and the support of the contacts she had made over the years, the Mavis Nye Foundation was finally registered in April 2017.

Mavis said: “I’m delighted to set up this Foundation because I know how it feels to be given 90 days to live and feel like you have nowhere to go and no one to talk to… I don’t want others to have that feeling of abandonment, I want them to have hope that you can live with a terminal illness and fight.”

The objectives for the Foundation include:

• The relief of hardship by providing aid to mesothelioma patients in the UK requiring assistance to access medical treatment, particularly experimental medical treatment

• The advancement of laboratory and clinical research in the UK for the treatment of mesothelioma and other asbestos-related diseases

• To assist in the treatment for and care of mesothelioma patients, in particular but not exclusively, by awarding scholarships or grants tenable at any British university or institution of higher education for health professionals in financial need and endearing to work primarily in the field of mesothelioma nursing in the UK.

A website and launch event for the Foundation are being planned – keep an eye on social media for more details.

www.onestopmesothelioma.com
www.royalmarsden.wordpress.com
Twitter: @Grandmamavis

Clinical trials: we want your views!

The British Lung Foundation is conducting a survey for people with mesothelioma about views on clinical trials and if there are difficulties that stop people taking part. The survey is very short, it will take 5-10 minutes to fill in and is completely anonymous.

You will need to set aside time to do the survey all in one go and it must be completed by patients, not carers. The results will be analysed and shared with the British Lung Foundation, mesothelioma researchers and patient support groups to see what can be done to encourage more people to take part in clinical trials. With thanks to Mesothelioma UK and the Asbestos Victims Support Groups Forum for their input and sharing this survey with their members.

Please submit your views via the survey link by 5pm on Tuesday 11 July 2017. Survey link: www.surveymonkey.co.uk/r/BLF_mesotheliomaSurvey
Mick George Ltd joins Mesothelioma UK Corporate Donor Scheme

We’re delighted to welcome Mick George Ltd as a corporate donor. Mick George Ltd is one of the leading suppliers to the construction industry and is supporting Mesothelioma UK to confirm its commitment to raising awareness of the dangers of handling asbestos.

Mick George Ltd has grown to become one of the leading suppliers to the construction industry in the heart of East Anglia and East Midlands.

Operating with a single tipper truck in 1978, the company’s commercial fleet size has now grown to be in excess of 400 HGV vehicles. It specialises in Bulk Excavation & Earthmoving Services, Demolition and Asbestos Removal, a wide range of Skip Hire and Waste Management Services and Aggregate & Concrete Supply, as well as the most recent Facility Management & Retail offering.

Mick George Ltd provides a range of specialist services including Asbestos Removal and the company has pledged to donate a percentage of the income generated from this particular service over the next 12 months to Mesothelioma UK.

Mick George Ltd will also be involved in fundraising events and activities for Mesothelioma UK with all funds going to awareness raising campaigns, training and education for Clinical Nurse Specialists, and research into treatment and clinical trials to find a cure for this deadly disease.

Michael George, Contracts Director at Mick George Ltd said “The link between mesothelioma and the construction industry is particularly high and we want to play a part in its prevention. Through our comprehensive Asbestos Management service, we recognise that we have a responsibility to support any health related issues and that’s why we’re partnering with such a respected organisation as Mesothelioma UK to try and improve the situation.”

Liz Darlison, Mesothelioma UK Director of Services and Consultant Nurse at UHL, added: “Mick George Ltd has a history of community support and philanthropy, with a genuine dedication to supporting related charities.

“The UK has the highest incidence of mesothelioma in the world and with asbestos being at the heart of this disease, there’s a real connection here with Mick George Ltd’s expertise in surveying, stripping, carriage and disposal of asbestos. We are delighted to welcome them on board and together we will raise awareness and continue to help patients with mesothelioma, their carers and families across the UK.”

Funding supports vital MesobanK project

MesobanK is a mesothelioma tissue biobase, based at Papworth Hospital NHS Foundation Trust, collecting tissue and blood samples from patients all over the UK.

MesobanK supplies researchers with these samples to use in mesothelioma and asbestos related research. Originally funded by the British Lung Foundation and Mick Knighton Mesothelioma Research Fund, the MesobanK project has also received additional funding from the British Lung Foundation from the Victor Dahdaleh Foundation.

The funding is being used to continue to support MesobanK’s sample collection, curation and distribution, as well as establishing a programme of clinical research fellows/post docs to build future research leaders in mesothelioma.

CONFIRM up and running

The CONFIRM clinical trial is now open at two sites - Leicester and Aberdeen – and will also be opening soon in Glasgow and Wythenshawe. The first patients have been randomised in Leicester.

CONFIRM is looking at nivolumab to treat mesothelioma that has come back after chemotherapy treatment (relapsed) and is supported by Cancer Research UK.

Doctors treat mesothelioma with chemotherapy. After chemotherapy if the mesothelioma comes back, the aim is to control symptoms. This is called active symptom control. Researchers want to find out if nivolumab can help these people.

Nivolumab is a type of immunotherapy drug called a monoclonal antibody. It works by stimulating the body’s immune system Open a glossary item to recognise and kill cancer cells.

Research indicates that nivolumab could help people whose mesothelioma has come back after chemotherapy. (But it isn’t known if it as good as active symptom control. In this trial, most patients will have nivolumab and some will have a dummy drug (placebo Open a glossary item).

The main aims of the trial are to find out how well nivolumab works for people whose mesothelioma has come back after chemotherapy, how safe it is, and how it affects quality of life Open a glossary item.

Mesotheioma study day: Many Stories Told – Many Still to Tell

A Mesothelioma Study Day was held in May at the Principal York Hotel. The day was jointly organised by the Irwin Mitchell AFD Team in Leeds and Simon Bolton, Mesothelioma UK Clinical Nurse Specialist for Yorkshire & Humberside.

The event was co-sponsored by AstraZeneca, Bristol Myers Squibb, Merck Sharp & Dohme and Rocket Medical. Mesothelioma UK nurses, Lorraine Creech, Leah Taylor and Karen Lord also attended.

The event was attended by 48 delegates, including healthcare professionals from Yorkshire and the North East of England, and patients and carers mainly from the MESSY (Mesothelioma Support Yorkshire Group).

The first speaker of the day was Greg Byrne, Director of RS Asbestos Consultants based in Burnley, Lancashire. Greg outlined the ‘Horrible History’ of how asbestos came into the UK and why and how it became so widely used.

He went on to explain why it continues to cause problems, the steps which are being taken and will need to be taken in the future to safely remove it from existing property.

Dr Alison Gill, Consultant Respiratory Physician at York Teaching Hospitals described the various techniques currently used by clinicians to make an accurate diagnosis of mesothelioma and improve the chances of choosing the most appropriate management pathway for the individual patient.

Karen Lord, Mesothelioma UK Clinical Nurse Specialist (Leicester) then shared ‘Top Tips for Mesothelioma Symptom Management.’

Then Michael Rawlinson QC gave a presentation on some topical legal matters. These included a possible link between the use of talcum powder, particularly in the 1960s and 70s and women developing mesothelioma.

After lunch, Dr Prussia Jain, Consultant Clinical Oncologist from the Leeds Teaching Hospitals spoke about systemic therapies and the current range of clinical trials, particularly those available to patients in Yorkshire and Humberside.

This talk was followed by a presentation from Mr John Edwards, Consultant Thoracic Surgeon at Sheffield Teaching Hospitals, entitled ‘The Role of Surgery and MAR52’ - the current national trial which is recruiting very well across the UK, with the surgery currently being performed by John in Sheffield and the Leicester Thoracic Surgical Team at Glenfield Hospital.

Simon Bolton then showed a selection of video clips of mesothelioma patients, including a clip of Dr Kieran Sweeney, who describes his experience with healthcare professionals with a view to encourage a more understanding, caring and personal approach from all involved.

If you haven’t seen it, it is well worth 12 minutes of your time. Visit www.youtube.com and search for Dr Kieran Sweeney.

Thank you to all the speakers and the guests who attended. A raffle at the event raised £106 which is to be split between Mesothelioma UK and MESSY.

Helping to Make Mesothelioma Matter in Scotland

Last year, Julie Roberts started a campaign in Scotland to make Mesothelioma Matter after she lost her Dad and Uncle to the disease in 2015. They both caught mesothelioma simply by going to work - one a joiner, the other an electrician. They were diagnosed four weeks apart and both died just eight short months later.

When the Scottish Government launched their Cancer Strategy ‘Action & Ambition’ in March 2016, Julie noticed that mesothelioma was not referenced at all.

Consequently, Julie is asking for people to join her in pledging support for the improvement of early detection, diagnosis, treatment and research into mesothelioma in Scotland, and for the inclusion of it in the Scottish Government’s Cancer Strategy.

You can pledge your support at www.mesotheliomamatters.org
The International Symposium on Malignant Mesothelioma

By Mesothelioma UK Clinical Nurse Specialist and Team Leader, Lorraine Creech

Our team of Mesothelioma Clinical Nurse Specialists plus Liz Darlison, Director of Services and Jill Lemon, Fundraising Manager were fortunate to be able to attend The International Symposium on Malignant Mesothelioma in April. The symposium was arranged by the Mesothelioma Applied Research Foundation (MARF) and was held at the Clinical Research Institute in Bethesda, Maryland, USA.

Friday 25 March was the International Mesothelioma Nursing Symposium held at the University of Maryland School of Nursing in Baltimore. Many thanks to Melissa Culligan for arranging this event and inviting us. The School of Nursing was established in 1869 and is ranked number 1 for Clinical Nursing Leaders and the Nursing Informatics Masters Programme.

Mesothelioma UK nurses participated in the symposium, delivering various presentations. Liz Darlison presented on the global perspective and she also described the achievements and strategy of Mesothelioma UK. Anne Mойlan described cancer nursing in the UK and Lorraine Creech spoke on the ‘hub and spoke’ model of nursing. Leah Taylor described the UK mesothelioma community.

Helena Stanley shared the latest morning session provided by our American colleagues. There was considerable discussion about the differences in our nursing services. The USA does not have Clinical Nurse Specialists in the same specific roles as we have in the UK. In the afternoon we had a tour of the Cancer Centre Hospital after viewing several simulation suites in the School of Nursing.

The main symposium was held from 27-29 March. MARF is a non-profit collaboration of patients, families, physicians, advocates and researchers. It is dedicated to offering support and helping with the provision of the most up-to-date information on treatment options, connecting with mesothelioma treatment specialists, and providing assistance, emotional support and peer support. So it has lots of similarities with Mesothelioma UK but operates in very different health care systems.

The scientific programme focused on trials, immunotherapy, genetics, surgery, radiotherapy and other treatments. There were over 80 scientists/international speakers present from the forefront of mesothelioma treatment and support.

The learning objectives were to:

- Recognise the current approaches and strategies for early detection and screening of mesothelioma
- Demonstrate the best methods to implement multi-disciplinary tumour boards into community practice
- Examine evidence-based therapeutic regimens for mesothelioma for early stage and advanced mesothelioma
- Distinguish evidence-based therapeutic regimens for mesothelioma based on biomarker status and patient/ tumour characteristics
- Define best practice regarding the application of targeted therapies for mesothelioma in Konskie and subsequent settings
- Describe current and emerging immunotherapy strategies in the context of clinical trials findings and patient selection in mesothelioma
- Integrate clinical data on maintenance in mesothelioma to determine which patients would benefit most from a maintenance regime
- Review the clinical significance of optimal biopsies, specimen flow and molecular testing for personalised medicine in non-academic settings
- Illustrate the molecular pathways that hold promise for therapeutic intervention for mesothelioma

Alongside the scientific programme there were sessions for the general public, patients, caregivers, families and bereaved, for general exchanges of information and support. Many were keen to hear about our working practice in the UK as patients and carers in the USA often have to co-ordinate their own care. Patients, carers and professionals were keen to hear about the role of the Mesothelioma UK Nurses and we were integral to the support sessions, one of which was chaired by Anne Mойlan and another by Liz Darlison.

Wednesday was advocacy day when we joined patients and advocates at Capitol Hill to lobby for a National Mesothelioma Registry in the USA and for funding to be maintained from the Department of Defence to support research necessary to find a cure for mesothelioma. This is particularly important as the military have a higher risk of asbestos exposure. Approximately one third of cases have been shown to involve naval personnel or civilian workers in naval dockyards.

Following this we journeyed home full of information, motivation and appreciation for being able to attend.

Here in the East Midlands we are busy organizing our Action Mesothelioma Day so if you live in this area we will be holding our Service of Reflection and Hope at the Leicester Cathedral at 2pm on the 7th July and anyone is welcome to come and join us. We have some wonderful speakers this year including Linda Lakin who will be speaking about her journey with mesothelioma, Yeone Blenc a classical guitarist will be playing periodically through out the day and will play a reflective piece before the close of service where Doves will be released from the cathedral grounds and then refreshments of tea and cake will be served inside the cathedral.

Action Mesothelioma Day is a very important day, it raises awareness about the dangers of asbestos and the legacy it has left. It brings families together to remember those loved ones who are no longer with us and gives support and hope to those living with mesothelioma. It helps to share what is happening in the mesothelioma community with new treatments and trials. Our priority is ‘To Make Mesothelioma Matter’ and we can only do this through our work and supporting the campaign for continued funding for more research.

Have you planned what you will be doing on this special day, if not you can always join one of the events taking place in your area that Patient Support & Asbestos Support Groups are organizing and they are listed on our website. If you want to hold a small gathering yourself, let us know about it and we can put it on ‘Facebook’ and on our website, and please do remember to send in your photos and write ups for the autumn newsletter.

Malignant Mesothelioma is a common and often fatal cancer that affects the lining of the lungs, chest, and other body cavities in approximately 3,000 people each year in the United States. It is caused by inhalation of asbestos fibres and has a latency period of 40 years or more. There is no cure and currently no FDA approved drug for the treatment or prevention of malignant mesothelioma.

Summer is here and the sun seems finally to have found his hat! This makes us forever hopeful for those warm sunny days when we can get busy in our gardens and tend to our lilies. The Forget-Me-Not’s are out which always brings to mind Action Mesothelioma Day, where our thoughts are with those living with mesothelioma and those who have lost.

Marching for Meso in March was very well attended and we are so looking forward to next year where we hope more of you will come and join us.

‘Muffins for Meso in May’ has been just fabulous and yet again you our wonderful sponsors, fundraisers and supporters have got on board and are raising awareness through the work place, at home, in schools, hospitals and just anywhere you can get a table and a tea pot which is exactly the result we wanted. Please keep sending in your pictures and stories to enter our competition for our three categories ‘The Best Dressed Muffin’, ‘The Most Unusual Muffin’ and ‘The Best Muffin Recipe’ I think our job of judging those will be just as difficult as it was last year because what we have received so far look and sound so wonderful and very delicious.

All photos received will feature in our next newsletter and if you have a story you want to tell about your personal fundraising experiences do send it to us, your stories and pictures are powerful, they come from the heart of those who know what having a mesothelioma diagnosis really means.

We are here to help anyone who has been touched by mesothelioma, so don’t struggle alone. We have a wide range of research in all fields to help make things easier for you and your family, just pick up the phone and ring our Freephone number 0800 169 2409 or email us at mesothelioma.uk@thrifts.uk or contact us through our ‘Facebook’ page and leave us a message and we will get back to you.

I would like to wish everyone a very long and warm summer.

Linda Lakin
Fundraising & Marketing Manager

Django Bennett-Clarke

Django Bennett-Clarke is an inspirational young man, aged just 9 years old, who took part in his very first ‘Greystoke Junior ‘Tzarac’ Triathlon’ in memory of his dear Nana, Maureen Bennett, who died from mesothelioma in December 2015 and who he misses very very much.

This is what Django had to say…

“My name is Django and I am nine years old. I am raising money for Mesothelioma UK because my Nana died from this cancer. She got it because she came into contact with asbestos. My Nana was very strong and brave and I miss her very much. I have never done anything like a triathlon before but Nana encouraged me and I want to try and do this for her charity.”

Well Django has raised an amazing £129.75 including gift aid for Mesothelioma UK and he very proudly wore his Mesothelioma UK T-Shirt to help raise awareness. Well done Django you are a super star.

Here is a picture of Django and his lovely Nana, Maureen and below Django finishing his very first Triathlon.

Mesothelioma UK Charitable Trust
Fundraising News

Summer is here and the sun seems finally to have found his hat! This makes us forever hopeful for those warm sunny days when we can get busy in our gardens and tend to our lilies. The Forget-Me-Not’s are out which always brings to mind Action Mesothelioma Day, where our thoughts are with those living with mesothelioma and those who have lost.

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I would like to wish everyone a very long and warm summer.

Jill Lemon
Fundraising & Marketing Manager

Mesothelioma UK • Freephone 0800 169 2409 • www.mesothelioma.uk.com
Details of all sponsorship, donations, fundraising and successful grant applications are posted on our website
Mesothelioma UK Newsletter - Summer Issue 2017

My Wonderful Dad, Dermott Dougan - 04/12/54 -19/03/17

“My wonderful dad, Dermott Dougan, was born in Northern Ireland and it was there that he met my mum, Deirdre, and they decided to start their married life together in Manchester. Together they had me, their only child, Amanda in 1973. Dermott worked as a joiner/shop fitter throughout his career where unfortunately he was exposed to asbestos when in his twenties, discovered he had mesothelioma at Christmas 2015 and sadly died in August 2016, giving him very little time with his family who are still living as at the moment there is no cure. The only treatment available to my grandad is pain relief, and 3 treatments of radiation again to help with the pain. They are currently 2 other cancer related terminal treatments will not beat this cancer, which is why it’s important awareness is spoken. Myself, my husband and possible other family members have taken part in an 8 mile sponsored charity walk in Newcastle for Mesothelioma UK charity and have raised £367.05.”

Mysley and my sisters are going to be taking part in this years run forcolour on 1st July to raise money for Mesothelioma UK. The charity is dedicated to providing specialist mesothelioma information, support and education for improving care and treatment for all UK mesothelioma patients and their carers. Our stunning granadad was diagnosed with this illness February 2016 after working as a labourer at The Highland Council back in the early 80s. He has been a fighter throughout this past year and me and my sisters would like to fundraise to help in such a difficult situation and have seen first hand what Mesothelioma has done to our family. We would like to raise as much as we can to give other people suffering from this illness the care they need and deserve. Thanks to all that donate in advance...a wonderful husband, father, son, brother, and dear friend.”

Amy Davidson & Sisters Run For Colour 2017

Nic Bracegirdle - Walking for my Dad, Roger

“Told on the March for Meso challenge and walked 10,000 steps a day during March to support the charity and because my dear Dad lost his fight with Mesothelioma in Aug 2016. With the help of my friends and supporters I raised £587.50.”

David Baugh and Phil Jackson - A Marathon for Roger Bracegirdle

“Phil and I finally signed up and there was no going back! Over the May weekend I joined a group who was walking 30 miles of the Guernsey Coastal Path in aid of their chosen charity. My chosen charity was Mesothelioma UK as it supports people with a diagnosis of Mesothelioma and their families. I raised £366.86 and would like to thank all of my wonderful sponsors.”

Angela Tod - Guernsey Coastal Path Challenge

“Over the May Day bank holiday weekend I joined a group who was walking 30 miles of the Guernsey Coastal Path in aid of their chosen charity. My chosen charity was Mesothelioma UK as it supports people with a diagnosis of Mesothelioma and their families. I raised £366.86 and would like to thank all of my wonderful sponsors.”

Anthony Barlow - Barlow’s gonna run 13+miles for Batsly!

“On May 25th last year I lost a great mate and work colleague- Chris Llister to an Asbestos related term cancer called Mesothelioma. Mesothelioma has no cure, and it can stay in your body undelected for anything up to 40yrs. So in Chris’s memory I will run my first half marathon on 28th May as I want to raise funds for Mesothelioma UK to support the work they do and because this charity helped Chris and his family in many, many ways and deserves much needed support for this valued and important work.” If you wish to support Anthony visit his Just Giving page https://www.justgiving.com/fundraising/Anthony-Barlow2

Linda Lakin - Volunteer and Patient of the Leicester MELU Luncheon Club

“My Grandfather was diagnosed with Mesothelioma cancer earlier this year and has been given an estimate of 12 months to live. The whole family has been devastated by this news especially my Granddad and my Nan, going from a normal life to be full of medication and pain. Mesothelioma is an asbestos related cancer, that many people were exposed to in 1940 right through up until 1986, where there was finally a ban. Employers failed to inform staff of risks that working with asbestos will cause later in life. Symptoms of exposure to asbestos do not develop for many years, and in many cases by the time it is diagnosed the damage has already been and too late. Hence the reason why we are trying to raise awareness for this terrible disease so people can get checked before this awful thing takes over.

We are also fundraising for this charity so that one day maybe they can find a cure for this, as at the moment there is no cure. The only treatment available to my grandad is pain relief, and 3 treatments of radiation again to help with the pain. Chemotherapy is an option but family treatments will not beat this cancer, which is why it’s important awareness is spoken. Myself, my husband and possible other family members have taken part in an 8 mile sponsored charity walk in Newcastle for Mesothelioma UK charity and have raised £367.05.”

June Allingan – London Marathon

“Despite having a bad throat and a heavy cold I managed to cough and splutter my way round the marathon and I FINISHED IT IN 5 HRS 6MINS. Money raised so far is £1,701.25 so a big thank you to all my sponsors and I have some fab photos to share, I particularly like the one with Steve Cram wearing my running club bobble hat, and the other one is where you could dance for 5 mins and earn a £5 donation from Virgin Money - so I did. Cheers all June.”

Charlotte Thornton – In Memory of my lovely father, Graham Thornton

“Last year so many of you supported my climb up Kilmijarv in support of Mesothelioma UK, the biggest supporter however was my father who lost his battle with Mesothelioma 6 months ago. In his memory I am endeavouring to raise more money for Mesothelioma UK by completing EVEREST Base Camp but I’m beginning this challenge by taking part in the Southampton Half Marathon before my challenge and finishing with Snowdonia half Marathon. Much like his final week he fought and never gave up and when it comes to Mesothelioma and bringing as much awareness to this disease and support to those affected by it, I refuse to either. Thank you for all your support”. To support Charlotte visit her Just Taking page https://www.justgiving.com/fundraising/charlotte-thornton/
**Dawn Parker - For My Dad**

Cycling a 1,000 miles for 1,000 pounds

"My Dad Lyndon Parker has never smoked a single cigarette in his life, so we were devastated in October 2016 when he was diagnosed with Lung Cancer. After numerous tests and a biopsy it was confirmed that he had Mesothelioma.

After numerous tests and a biopsy it was confirmed that he had Mesothelioma.

I have decided to take on the challenges of cycling a 1,000 miles between April and July, these miles will be a combination of social rides and sportives, the first being the Tour de Gwent on Sunday 9th April - 58 miles, then the Hero sportive on the 23rd of April - 32 miles, Iron Mountain 24th June - 40 miles, Veloton Wales 9th July - 68 miles, Landrord Festival Sportive 16th July - 68 miles.

I am to book on more and will be providing updates as when I do, so please donate to my chosen charity and help raise awareness of Mesothelioma and help to support people who are diagnosed with this cruel illness. Throughout all of this it has taught me - life is a gift, so live in the present, eat the cake, buy the bike, book that holiday, the rainy day savings are for a rainy day.

Another simple way to support the charity is when we or our carers plan our funeral and choose to donate to Mesothelioma UK instead of flowers.

**Mavis Nye**

Supporting Meso UK

Mesothelioma UK is our Charity and many of us would like to raise funds but don’t know how. One simple way for a more long-term help is to leave the charity money in our wills.

Lots of people do for other great charities, which is wonderful to do so maybe we can suggest to our relatives to do the same for Meso UK. Gifts in wills are an amazing way of continuing your support long into the future.

We have to visit a Lawyer over our claims for Mesothelioma Compensation so we could do it at the same time, if you’ve already written your will it’s never too late to amend or even write a new one. We are told it’s our affair to do so that is what we do.

Another simple way to support is when we or our carers plan our funeral and choose to donate to Meso UK instead of flowers.

Well that’s got the morbid things out the way so let’s talk about happier ways we can help. We can do many things which are easy like invite neighbours around for a coffee morning, open the Just Giving or a Fund a Meal page to share amongst our friends and family.

They of course, being fit can do fun runs or walks where even our youngsters can join in. Please get together and plan something... Fundraise for Mesothelioma UK.

**Niamh Sherwood runs Reading Half Marathon for Mesothelioma UK**

On 19 March 2017 Niamh took part in the Reading half marathon to raise funds for Mesothelioma UK. It was her sixth Reading half marathon, she says,

"Each race is different and there is always a surprise. Last year there was a man running with a fridge on his back and this year it was a runner with a delivery box on his back. A few years ago in the Green Park Challenge, a race held immediately before the Reading half marathon for younger runners, I recall the youngest who had run a good race and stopped just before the line to somersault over the finish line. That still makes me smile.

Putting one foot in front of another is enough of a challenge for me and I save my spare energy for my annual frugal around the course. I felt I had not done enough training and I was worried that my time would be rubbish but as always none of that mattered one jot. Myself and the thousands of other runners around the course with the amazing support from the lovely people of Reading who turned out as always in great numbers to cheer on the runners providing wonderful treats along the way, jelly babies, fruit, nuts and even beer if you were up to it! This year Niamh raised £398.94 for Mesothelioma UK.

"I am extremely grateful to my family and friends who donated this year and who donate every year. In my daily work I see how mesothelioma affects the lives of sufferers and their families and it is comforting and reassuring to know that Mesothelioma UK continues to provide wonderful support and assistance and guidance in such an extremely difficult time. It is a privilege to support such a worthwhile charity."

**Richard Hoyle - Walking 100 miles in a Week**

"In May I walked 98 miles of the Camino Way for Mesothelioma UK Charitable Trust because it recently lost my wife Annie to mesothelioma. First, I want to thank you all for supporting me. I wanted to raise money for better research into the treatment and prevention of Mesothelioma. It is a deadly cancer caused by breathing in asbestos dust. There’s no cure, over the next 35 years 60,000 people will die from mesothelioma – unless new treatments are found. In October 2016, my beautiful wife Annie passed away due to Pleural Mesothelioma as a result of exposure to asbestos when she was a primary school teacher in the 70s. The British Lung Foundation believe unless a cure is found we will see thousands of deaths of ex teaching staff who were exposed to asbestos in the 60s, 70s and 80s." Richard raised £2,116.77.

**Kath Burrows Grand Charity Night**

Kath and Friends held their annual Grand Charity Night on Friday March 3rd at The Elms Social and Service Club in Leicester in memory of her dear husband Les. The evening was a wonderful night which was sponsored and supported by the Soul Providers along with Chris Robins, Hollie & The Dedicators Band, Steve Sinatra and The Foundations with Hughes Montgomery and while raising the roof they raised an amazing £1,049.92.

Kath and family would like to thank all those who have helped out and supported this event.

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**Jake Allingham and Warwick University Men’s Football Team, 12 hour Walk from Boundary Park Oldham Athletic to Anfield Liverpool in memory of his Grandad, Mike Allingan**

"As the terrible weather, it poured down all day... and the fact that instead of the 38 miles it takes from Oldham Athletic FC to Liverpool FC we actually ended up doing 43.5 miles I might be good at the running but my navigational skills leave a lot to be desired’… we were absolutely devastated.

Jake’s dad, Steven Allingan, his Grandma June Allingan and his cousin Hannah Allingan said that the event was a huge success and that they would like to thank everyone who took part.

The team raised £398.94 for Mesothelioma UK.

"Mavis Nye’s UK Newsletter - Summer Issue 2017 - Running 2 full & 4 half marathons throughout 2017 for Mesothelioma UK charitable trust because improving support and access to treatment is vital."

"Throughout 2017 I will be running in events around the UK to raise awareness of this devastating incurable disease and hopefully generate some much needed funds to support those affected by this asbestos related cancer. I’ll end the year with one final run over a much shorter distance, racing into the icy waters of the North Sea during the festive season!"

- London Marathon
- Leeds Half Marathon
- Great Manchester Run
- Durham Coast Half Marathon
- Great North Run
- Yorkshire Marathon
- Sunderland Boxing Day Dip
- Reading Half Marathon
- Leeds Half Marathon
- Sprint 16th July - 68 miles.
- Sportive 16th July - 68 miles.
- Driving 100 miles in a Week
- Fundraise for Mesothelioma UK.

If you would like to support me then please visit my Just Giving page. https://www.justgiving.com/fundraising/Simon-Bolton2"

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"My dad was a carpenter so he spent decades working hard in asbestos environments with no protection - little did he know this would so quickly take his life in later years. This type of cancer lays dormant for years and then when it quickly take his life in later years. This type of cancer lays dormant for years and then when it finally rears it's ugly head - BANG!!! it’s too late and"

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But wait, there is a man running with a fridge on his back and this year it was a runner with a delivery box on his back. A few years ago in the Green Park Challenge, a race held immediately before the Reading half marathon for younger runners, I recall the youngest who had run a good race and stopped just before the line to somersault over the finish line. That still makes me smile.

Putting one foot in front of another is enough of a challenge for me and I save my spare energy for my annual frugal around the course. I felt I had not done enough training and I was worried that my time would be rubbish but as always none of that mattered one jot. Myself and the thousands of other runners around the course with the amazing support from the lovely people of Reading who turned out as always in great numbers to cheer on the runners providing wonderful treats along the way, jelly babies, fruit, nuts and even beer if you were up to it! This year Niamh raised £398.94 for Mesothelioma UK.

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"The Tour of Gwent is now complete, so I have cycled my first 65 miles of the 1,000 this was 58 miles for the event itself and 7 miles as I also cycled there and back so if you would like to support me please do visit my Just Giving page, thank you." https://www.justgiving.com/fundraising/Dawn-Parkers-Dad"

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For those of you who don’t know what this is, it is asbestos poisoning, it is a cruel and devastating illness and you can imagine the shock and fear when we were also told that there is no cure. My dad was a carpenter so he spent decades working hard in asbestos environments with no protection - little did he know this would so quickly take his life in later years. This type of cancer lays dormant for years and then when it finally rears its ugly head - BANG!!! it’s too late and cancer lies dormant for years and then when it quickly takes his life in later years. This type of cancer lays dormant for years and then when it finally rears its ugly head - BANG!!! it’s too late and cancer lies dormant for years and then when it finally rears its ugly head - BANG!!! it’s too late and

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Sadly my dad passed away on the 8th December 2016 just a few months later after being diagnosed. There is not a day that goes by without being reminded of the suffering that he went through, and the lack of support and knowledge we had about this illness. But my dad, he never complained, he just got on with it, and he was always giving us the thumbs up to say he was ok, but we knew otherwise. My dad was outgoing and loved life but sadly he was taken away too soon. Cancer lies dormant for years and then when it quickly takes his life in later years. This type of cancer lays dormant for years and then when it finally rears its ugly head - BANG!!! it’s too late and cancer lies dormant for years and then when it finally rears its ugly head - BANG!!! it’s too late and cancer lies dormant for years and then when it finally rears its ugly head - BANG!!! it’s too late and cancer lies dormant for years and then when it finally rears its ugly head - BANG!!! it’s too late and cancer lies dormant for years and then when it finally rears its ugly head - BANG!!! it’s too late and cancer lies dormant for years and then when it finally rears its ugly head - BANG!!! it’s too late and
David Staley - One Lung, One Life, One Hundred Miles

29th October 2015 - One day before our daughter’s 6th birthday, 3 weeks after my wife’s 40th birthday and 3 weeks before my 40th birthday, our lives changed forever! I was diagnosed with mesothelioma, a terminal cancer related to exposure to asbestos. An under-funded, little known cancer, with an average life expectancy of just 12-18 months.

We were faced with tough choices, and three weeks later, to give me the best chance, I had my left lung removed. I was home to spend Christmas with the family whilst I recuperated and regrouped before starting the gruelling chemo in January 2016.

Thankfully, so far the treatment has been successful. I have now outlived the first milestone of 18 months and there is no sign of the disease - I feel very blessed. But we are told one day it will return and when it does, we want there to be a cure! I need to see our kids Joshua & Erin grow up, get married and have children of their own. I want to ensure I get across that finish line!

I am honoured that they are supporting me and their wives have been amazing support - Claire & Paul and Jamie & Fiona. They will be supported by best mate Stephen Colley & brother-in-law Simon Ingyon. They also have a high target as I'm not certain I will get around the 26.2 miles. I want to do something that would make him proud. I want to do something so he can see me do it. I want to do something that would make him proud so I'm fundraising in his memory, and hopefully one day we will defeat this cruel disease.”

Jamie Fittock - Rotterdam Marathon for my Dad

“On 19th December my dad Richard, sadly passed away after a brave fight against mesothelioma, its been a very tough and sad time, but we cherish all the great memories we had with him and at the very least his now out of pain. I wanted to do something that would make him proud so I’m fundraising in his memory, and hopefully one day we will defeat this cruel disease.” Jamie raised £980.00.

Victoria Bennett and Family - Raising Funds in memory of Maureen Bennett

“In March 2014, my Mum visited the GP suffering from a persistent cough, shortness of breath and tiredness. On Christmas Eve 2014, after a harrowing year of tests, surgery, illness and misdiagnosis, I sat with my Mum in a hospital room as the consultant said these words: “Maureen, you have terminal malignant mesothelioma. I am sorry. There is no cure,” But my Mum knew that. She had already watched her sister and brother die from the same disease.

In December 2015, 11 months after this meeting, I sat beside my mother as she died. My Mum and her sisters were exposed as children through their father’s work clothes. That is all it took. Asbestos is Dangerous, and my family and I want to do something about that. Before my Mum died, I told her I would do what I could to help others like her, that is why I am supporting Mesothelioma UK, they helped me care for my Mum when she had to face the impossible. So our challenge will be to walk 1 Million steps for Mesoth.”

Update: “I made it to our 1 million steps for mesothelioma – in fact I bustted right through it, reaching a total of 1,451,673 steps by December 1st. With Adam and Django walking alongside me, in 3 months, we walked over 1500 miles between us raising £445.00.”

The Plymouth Morris Men

On bank holiday May Day morning when most good people were still in bed nuzzling away, the Plymouth Morris Men celebrated their final dance of the year at their annual sunrise Morris Dance. These wonderful Morris Men have been fundraising for a whole year for and in support of Mesothelioma UK and this was the most opportune time to present our new South West Nurse, Christine Jones with a cheque for £1,000.00, with a further personal donation from the wonderful Julian and his amazing jacket. This is what Christine had to say..."If these wonderful Morris Men can dance for a year for Mesothelioma UK's it was my pleasure to go and watch them on that rainy morning and many, many thanks for the early morning entertainment, the wonderful breakfast that followed and for all of your support, we really do appreciate it.”

Katie Sperring – 15,000ft Skydive for research in support of her lovely Dad

“On the 20th October 2015, my Dad and hero was diagnosed with Mesothelioma and given just 15-18 months to live. Mesothelioma is a rare form of cancer that is caused by exposure to asbestos. Mesothelioma has no known cure and a poor prognosis due to the time it takes for symptoms to arise. For many, once diagnosed it is already too late. My Dad has been the rock through this awful time and has handled this news with both dignity and positivity. I have always been so close and proud of my Dad and now even more so. He is a wonderful father and a doting Granddad (Grumps) and it is so unfair that he has been handed this fate but then that is always the way.

Now...I have always wanted to do a Sky Dive and for Christmas, my wonderful husband has bought me one and I am jumping from the aeroplane on our 5 year wedding anniversary on 3rd February 2017. Gereminco! I have now decided to use this amazing opportunity to raise as much money as I can for Mesothelioma UK. The Sky Dive is already paid for so all donations will go straight to the charity and be greatly appreciated. Due to the nature of this illness it needs as much research as possible so it can be diagnosed and treated sooner to hopefully bring about a more positive prognosis. Unfortunately, there is not much more that can be done for my Dad and we just need to appreciate every day but, if we can help anyone else with this research then that is the best we can wish for.” Katie did it and raised an amazing £1,444.41.

Catherine Toase & Team – Paul, Mark & Clare Thompson

“My dad, Richard, died of mesothelioma in 2014. He was diagnosed in March 2013, following a long period of tests, surgery and chemotherapy. We immediately set about raising funds for mesothelioma research in his memory.

We will never know how, or indeed when, my mother Joan was exposed to Asbestos, just that it robbed us of our good friend Clare and her brother Mark. They are taking part in The nuts Challenge on the 4th March, and I’m madly assault course!” And that they did and raised a wonderful £1,661.25.

Michael Nettleton – ASICS Manchester Marathon

“We will never know how, or indeed when, my mother Grandma far too early. Mesothelioma UK is a trustworthy and helpful source of information for people diagnosed with Mesothelioma we found it invaluable and I’d like to support it so others can continue to benefit. I’ve not set a high target as I’m not certain I will get over the 26.2 miles this time but I’m sure they would be grateful for any size of donation so on the basis that “Owt” is better than “nowt here goes!” Well he did raise a wonderful £281.25.

Sally Winterton

In April Sally took part in the London Marathon to raise awareness and funds for Mesothelioma UK, this is what she had to say...

“We want money for Mesothelioma UK? The government didn’t ban asbestos until long after they knew it caused cancer so mesothelioma is on the increase and its incidence will continue to rise for the coming years. Nearly 4 years and sadly it beat him on Christmas Eve. Mesothelioma is an asbestos related disease which is very hard to treat and is very resilient to standard treatments. More attention, research and money is needed to help patients to be offered and receive new treatments other than the standard drugs that are available at the moment. Me, my husband Paul and our good friends Clare and Mark Thompson are taking part! We will raise money for Mesothelioma UK, this is what she had to say.

Many people have no idea that they have been exposed to asbestos, it really could be ANYONE that gets the diagnosis. The charity is dedicated to providing specialist mesothelioma information, support and improved care and treatment. This type of cancer gets little media coverage and a lot of sufferers have never heard of it until they are diagnosed” Sally raised £1,729.14.

“With tough, choices, and three weeks later, to give me the best chance, I had my left lung removed. I was home to spend Christmas with the family whilst I recuperated and regrouped before starting the gruelling chemo in January 2016.

Thankfully, so far the treatment has been successful. I have now outlived the first milestone of 18 months and there is no sign of the disease - I feel very blessed. But we are told one day it will return and when it does, we want there to be a cure! I need to see our kids Joshua & Erin grow up, get married and have children of their own. I want to ensure I get across that finish line!

I am honoured that they are supporting me and their wives have been amazing support - Claire & Paul and Jamie & Fiona. They will be supported by best mate Stephen Colley & brother-in-law Simon Ingyon. They also have a high target as I’m not certain I will get around the 26.2 miles. I want to do something that would make him proud. I want to do something so he can see me do it. I want to do something that would make him proud so I’m fundraising in his memory, and hopefully one day we will defeat this cruel disease.”

Jamie raised £980.00.

Several years after my dad passed away, I decided to do something that would make him proud and that would help others like him.

The Plymouth Morris Men on bank holiday May Day morning were present to support our South West Nurse, Christine Jones, who received a cheque for £1,000.00 from the Plymouth Morris Men.

We were faced with tough choices, and three weeks later, to give me the best chance, I had my left lung removed. I was home to spend Christmas with the family whilst I recuperated and regrouped before starting the gruelling chemo in January 2016.

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Pamela Hamshaw – Easter Bunnies

Pamela Hamshaw, one of our long-standing fundraisers, excelled herself again for the Easter season by knitting and selling Rainbow Bunnies for Easter, raising the outstanding amount of £38.00. Pam has been raising money for Mesothelioma UK since 2010, ranging from holding outdoor information events to raise awareness, coffee mornings, sponsored walks and creating wonderful knitted items which are sold and all proceeds are donated to us. Pam is an invincible fundraiser who we are truly grateful for all her hard work.

Adrian Tew – The Great Wye Swimming Event

Sunday 21st May 2017, saw 82 swimmers line up on the river Wye in Monmouth, South Wales for 1k and 2k races in aid of Mesothelioma UK and St David’s Hospice. Our Ambassador for Wales, Bob McLaren, was there to start the race and to present the prizes to the winners at the end.

Bob said “It was amazing to see a record number of swimmers turn out to support our charities. I would like to thank everyone for their sterling efforts in raising funds and helping me to raise the profile of Mesothelioma and Mesothelioma UK in South Wales.”

It was the fourth Great Wye Swim 82 swimmers took part across four categories (1km Wetsuit & Non-wetsuit – 2km Wetsuit & Non-wetsuit) it was the biggest turn out in the history of the event. The weather was kind and the river was in great condition for the swim, the swim earlier in the week hadn’t affected it too much. The atmosphere on the day was superb with a good crowd watching and everyone contributed very generously to the two charities this year. £1,370.00 was raised to be split between Mesothelioma UK and St Davids Foundation (chosen as MSSC had a couple of staff members whose mother/grandmother had succumbed to the condition and was looked after by St David’s Foundation).

A huge thank you to all the participants and the staff at MSSC for making the event such a success.

A very special thanks to the Forest of Dean Scout Group who every year assist us by manning the safety boats and canoes to keep all the swimmers safe while in the river we couldn’t do the event without them and will be a great pleasure to have them as our nominated charity for next years event. The feedback from the event has been overwhelmingly positive and we hope to see everyone next year and make the event even more successful.”

Team Boyes Turner

The specialist asbestos disease team at Boyes Turner took part in the Windsor Colour Obstacle Rush on 20 May 2017 to raise vital funds for Mesothelioma UK, the UK’s leading mesothelioma charity.

Easter Bunnies

Easter, raising the outstanding amount

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Jane Halton – Raised £23 for making and selling handmade cards, pins, badges and pens in memory of her dear husband Bob and has now raised a total of £3015.70

Aly McCann – Held a Fair Raiser Night and raised £57.50 in support of her father-in-law

Emily Jackson – Held a Coffee Morning in March and raised £78.10

Sally Winterton – London Marathon £1,452.14

Jonathan Bates – London Marathon £367.50

Kelly Craven & the Sheldon Riders Team – raised an amazing £4,291.29 as their chosen charity in 2016 in memory of Sue Macgregor, Kelly’s dear mom.

Mary Law – Bluebell Ball at the British Legion, Lower Gornal, Raffle & Best Bluebell Dress £150.00

Sandra Holten & Ronald Schora – Steps Challenge in March walking 30 minutes each day for a month raised £198.50

Debbie Norman raised and donated £200.00 from hiring out her marquee

Edinburgh Woolen Mill Shop in Stapleton and Wigston raised £62.85 from their collection pots

Transac IntegraFin Services Ltd – held a Casual Dress Down Day on Friday March 13th and raised £950.00 and the Book People kindly donated £24.70 to Transac making the overall total raised £974.70

Murray Park Community School – raised £11.00 in support of Sam Pearch’s 10 marathons in 10 days bringing the overall total that Sam raised to an amazing £694.00

Vicky Smedley – Charity Football Match in Memory of her husband Richard raised £400.00

Merry Law – Bluebell Ball at the British Legion, Lower Bredon, Raffle & Best Bluebell Dress £150.00

Old Williamsonian Rugby Club – Annual Charitable Quiz Night raised £1,250.00 in memory of the clubs two friends Mr Painter and Mr Baron

Tony and Sheila Eccles – raised £140.00 from the Golden Wedding Anniversary Celebrations

Vicki Smedley – Charity Football Match in Memory of her husband Richard raised £400.00

Terry Surveys – Attended the Herts Building & Construction Awards Night auction and donated £200.00

Suzie Barnard – Raised £40.00 by selling Trolley Key rings in memory of her lovely Dad

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Paulette Hughes – raised £164.00 as her local Co-op in Golden Cross in memory of her dear husband Brian

Paula Bacon – kindly opened an in memory page for her dear father, Steve Gardner, ‘Stevie G raised £1,680.75

Kathie Pierry – The collection pot in the Bell & Crown Pub in Goole raised a wonderful £58.00

Vicky Smedley – Charity Football Match in Memory of her husband Richard raised £400.00

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Sue Macgregor, Kelly’s dear mom.

Sandra Holton & Ronald Schora – Steps Challenge in March walking 30 minutes each day for a month raised £198.50

Barbara Heaslop – Chopwell Drama Group held a recent production in memory of her husband Dave who had been a member for thirty years and raised £5000.00

Suzie Barnard – Raised £40.00 by selling Trolley Key rings in memory of her lovely Dad

Jonathan Bates – London Marathon £191.25

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Ain’t No Mountain High Enough

Dominic Smith, National Operations Coordinator - Industrial Disease, from Slater and Gordon (UK) LLP recently led a team of colleagues, family and friends up Snowdon in aid of Mesothelioma UK. Here’s how they got on...

"With a 7:30am start on an overcast bank holiday Saturday, the team gathered in the centre of Manchester to begin the drive to Snowdonia, North Wales. Two and a half hours later, under an ominous sky and having donned hiking boots and water proofs, the group embarked on the ‘Ranger Path’ up Snowdon.

The aim of the day was to raise awareness and much needed financial assistance for charities supporting those who have been diagnosed with asbestos related diseases, including the horrible cancer that is mesothelioma from which around 2,500 workers die each year in the UK. In the weeks running up to the day of the hike, the team sought sponsorship and donations for the Greater Manchester Asbestos Victims Support Group and Mesothelioma UK (including links to websites).

In addition to S&G employees, the group included family, friends and pets and at just after 10.30am the trek up the tallest mountain in England and Wales commenced. After a steep initial climb during the first 45 minutes it became clear that the ascent would be no walk in the park but the team was motivated by spectacular panoramic views, on what turned out to be a beautifully clear day. At around the half way mark, a natural enclave of rock provided much needed shelter from the harsh wind that had started to pick up and take its toll. But re-fuelled and rested the team set out on the more difficult part of the trek to the summit. Crucially, the summit and café remained very much in view as the team inched ever closer to their goal, the thought of a hot drink the light at the end of the tunnel.

The final section of the climb, the dreaded “zig zag” stretch proved difficult and progress was at times painstaking during this 2 hour stretch. The footing was unsure, the path made up of loose stone, slate and muddy foot holes but the team persevered and were glad to reach train tracks which signaled 20 more minutes to the summit.

The final stretch and summit were packed for one of Snowdon’s busiest weekends of the year, packed with people taking in the beauty of the surroundings, with the Snowdonia range dark lakes and the Irish Sea in the outer horizon.

As the team began its descent, there was a stark reminder of the dangers of the mountain, with rescue helicopters hovering above injured and fallen climbers.

The careful trek back to base was aided by warmer weather, the sun even making the odd appearance through increasingly broken cloud.

The first group arrived back at the cars approximately 20,000 steps later having completed the trek in a time of a little over 6 hours. The group included several members who were experiencing a mountain climb for the first time, but they were not the only ones suffering aches and pains after a long day. All completed the climb safely on what was a memorable day for the team.

A very special thanks to all our drivers that took us to and from the site as well as Lorraine Creech, Lung Cancer Specialist Nurse from Mesothelioma UK who was so inspired by our fundraising she also joined in the adventure." The team raised £994.35.

Dominic Smith
National Operations Coordinator
Industrial Disease