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
Specialist mesothelioma nurse appointed in Wales

We’re delighted to have funded our 13th Mesothelioma Clinical Nurse Specialist (CNS) in the UK. Sarah Morgan will be the CNS for Wales and will be based at the Hywel Dda University Health Board, West Wales.

In this two-day-per-week post, Sarah will work with colleagues across Wales to ensure that patients have access to specialist support and information, and to raise awareness of mesothelioma.

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

Sarah has been a nurse for over 30 years, having undertaken her initial nurse education at Glangwili General Hospital, Carmarthen and Swansea University. She has worked as a Macmillan Clinical Nurse Specialist in Palliative Care for Pembrokeshire and as Specialist Palliative Care Clinical Nurse Specialist for Papworth hospital Cambridge.

In her most recent post as a Macmillan Lung Cancer Specialist Nurse at Hywel Dda University Health Board, Sarah set up the lung cancer specialist nurse service and won an award for improving patient experience.

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 ($TOS$) and Mesothelioma 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 peritoneal mesothelioma cases in addition to our reporting on pleural mesothelioma.

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. This exercise will develop recommendations for best practice to be published as a ‘Mesothelioma UK Good Practice Guidelines’.

Holidays for people with cancer

Many patients, families or carers might be looking for a break away from it all.

For more information on available options, please contact the Mesothelioma UK Office on 01706 811844 or info@mesothelioma.uk.
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 peritoneal 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 removal of affected organs. This is then combined with heated intraperitoneal chemotherapy (HIPEC) to eradicate any remaining cancer cells.

Basingstoke and North Hampshire Hospital and The Christie Hospital in Manchester were originally designated as national centres for the assessment and management of PMP in April 2000. In addition to these two centres, the Good Hope Hospital in Birmingham, Ninevehds Hospital in Dundee and Mater Misericordiae Hospital in Dublin have been designated centres for the assessment and management of colorectal peritoneal metastases in 2013.

In July 2015, NHS England concluded there was insufficient evidence for the effectiveness of CRS and HIPEC for patients with peritoneal mesothelioma and as such this treatment is not currently funded by the NHS.

Despite the lack of funding and commissioning, CRS and HIPEC is performed at Basingstoke and North Hampshire Hospital for selected patients with peritoneal mesothelioma in collaboration with centres abroad collecting outcomes in an international registry. Patient selection for CRS and HIPEC is very strict, including CT imaging and staging laparoscopy (keyhole surgery to assess the extent of mesothelioma); unfortunately, the majority of patients referred to Basingstoke are considered unsuitable for surgery and will be referred back to their local team for systemic chemotherapy.

CRS and HIPEC is performed in a small subset of patients for either of 2 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; together, the 4 centres have set up the National Peritoneal Mesothelioma 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 biphasic or well-differentiated papillary mesothelioma) and 37 had high-grade mesothelioma (including epithelioid and biphasic mesothelioma). In 52 patients (68%), 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, 53% 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; after a major tumour debulking 46% 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. In these 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 launched the 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 Geor Doherty, Clinical Lead / 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. She also explained the background and referral and patient assessment process.

Dr Margaret Owen, Consultant in Anaesthetics and Chronic Pain has received training at the Queen Alexandra Hospital, Portsmouth. Given the distance and time requirements, this has not been an easy undertaking and it has required the support of her colleagues to backfill for her. Dr Owen and Dr Mitchell thanked Dr Paul Cook from Manchester for his mentorship.

The Cordotomy service at Beatson West of Scotland Cancer Centre is a way of helping patients with intractable chronic pain with cordotomy. Contrary to popular belief, the cordotomy procedure is a very safe pain management technique that involves only a minor cut to the neck and can be performed under local anaesthesia. It involves cutting a small section of nerve fibres that carry pain signals to the brain and it has been shown to provide significant pain relief in many patients.

The launch was a momentous occasion for the West of Scotland Interventional Cancer Pain Team. The aim of cordotomy is to help people who have had their pain put on hold due to significant complications and to provide them with a safe and effective treatment option. The team is committed to providing the best possible care to their patients and they are excited to see the impact the new service will have on the lives of those affected by pain.

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

The British Lung Foundation (BLF) is pleased to announce the first installment 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, which works closely with Mr Victor Dahdaleh to secure the generous £5 million donation for mesothelioma research projects, has awarded grants to two projects:

1. Dr Harry Nelmes, Consultant in Thoracic Surgery and Clinical Lead for Interventional Surgery at Papworth Hospital, will lead a team to develop a new technique for the treatment of mesothelioma. This technique involves the use of a novel drug to target cancer cells and prevent them from growing and spreading.

2. Dr Alison Mitchell, Senior Clinical Nurse at the University of Leicester, will lead a team to develop a new method for detecting mesothelioma at an early stage. This method involves the use of a new type of imaging technique that can detect small changes in the body before symptoms appear.

More than 200 researchers and clinicians from across the UK will be part of these projects, which aim to advance our understanding of mesothelioma and develop new treatments for this deadly disease.
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 on the day. We hope that you can take part in a local event 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-tr.nhs.uk.

Portsmouth - HASAG
12pm, Friday 30 June
The Inn Lodge, Burrfields Road, Portsmouth, PO3 5HA
A dove ballon release, raffle, tombola and buffet. Confirmed guest speakers are Liz Darlison, Mesothelioma UK Director of Development, and Regional Mesothelioma UK nurse specialist, Linda Jackson. The event will take place at the Provands Lodge’s Gardens. Thereafter, all are invited for lunch at St Mungo’s Hall. We have chosen to host our memorial to commensurate all those who have died and continue to die from asbestos related conditions.

Manchester - Greater Manchester Asbestos Victims 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.gmans@gmail.com or visit www.asbestos-victims-support.org.

Cambridgeshire - Papworth Mesothelioma Social Group
1pm, Friday 7 July
Hemmingford Abbots Village Hall, Hemmingford Abbots, Cambs, PE28 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
10am – 4pm, Friday 7 July
Croome Plaza, Wellington St, Leeds LS1 4DL
Meet the Researchers - this free event will enable mesothelioma patients, their families and healthcare professionals working in the field to meet researchers investigating treatments for the future and to discuss the day with an informal round table discussion allowing attendees the opportunity to hear about research topics first hand and to ask questions.

Local support groups and professionals from clinical and legal backgrounds will also be on hand to talk to people and provide information and advice.

Experts will include representatives from research projects currently supported by the June Hancock Mesothelioma Research Fund as well as a thoracic surgical presence to discuss the MARS2 surgical trial and a regional Mesothelioma UK nurse specialist.

Scotland - Clyde Clyde Action on Asbestos
12pm, Friday 30 June
Provands Lordship, St Nicholas Garden, Aberdeen
The event will take place at the Provands Lordship’s Gardens. Thereafter, all are invited for lunch at St Mungo’s Hall. We have chosen to host our memorial to commensurate all those who have died and continue to die from asbestos related conditions.

Leeds - The June Hancock Mesothelioma Research Fund and Mesothelioma UK
2:30pm, 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.
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Please contact Kate Slaven on 01480 830541 x4889, or kateslaven@nhs.net for more information.

Sheffield - South Yorkshire Asbestos Victims Support Group (SARAG)
Starting at 11am, Friday 7 July
Sheffield Cathedral, Church Street, Sheffield, S1 4HA

Guests and invited speakers include Sheffield Lord Mayor, Helen Street, Mesothelioma Lung Cancer Nurse Specialist, MPs, 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 Devonald 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 01709 360 672.

Mensaycide - Mansfield Asbestos Victims Support Group
11am, Friday 7 July
Hargreaves Building, Chapel Street, Liverpool L3 5AD
Public meeting with guest speaker, Dr Chris Warburton. 11.30am followed by a sponsored dove release at 12 noon at Exchange Flags to the rear of Liverpool Town Hall, assisted by local school children.

Return to Hargreaves Building for lunch and guest speakers including Steve Rotherham, Metro Mayor, Maria Guirri LON, Speaker from Imperial College London on mesothelioma research and Jeff Morgan, retired Occupational Physicist.

There will be a number of stalls, information stands and raffles throughout the afternoon. For more information, call 0151 236 1895, email info@asbestosstudies.org.uk or visit www.maov.org.

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.

The grant, for £21,795, has been awarded to Amy Kent, senior thoracic surgery research nurse at the Medical Innovation Development Research Unit (MIDRU) at Heartlands Hospital in Birmingham. The grant will fund a study into non-invasive diagnosis of mesothelioma using structured light plethysmography (SLP).

SLP is a new method of diagnosis that measures chest wall motion which has been shown to highlight differences according to the disease process causing identifiable pleural abnormalities on chest X rays or CT scans. It only takes five minutes for the patient to complete and the device is portable around the hospital. SLP uses squares of light in a chequerboard to detect chest wall motion by changes in the size of the squares as the patient breathes.

Amy said: “I must say that I am humbled, honoured, and at the same time excited to receive the award from Pat Stone Meso Support, Mesothelioma UK and the National Lung Cancer Forum for Nurses (NLCFN). This funding will give us a fantastic opportunity to transform the diagnosis pathway for Mesothelioma patients for the better.”

SLP is completely non-invasive and doesn’t require any specific movements by the patient. A pilot study at MDU/L using SLP with 15 patients found significant differences is chest wall motion and shows promise of a promising tool to help diagnose the cause of pleural disease such as the differences between mesothelioma and benign pleural thickening.

Liz Darlison, Mesothelioma UK Director of Services and Consultant Nurse, added:

“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 prospectively 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 buffet. Centre clinic prior to undergoing diagnostic pleural biopsy will be invited to join the study in the study by a suitably qualified member of the thoracic research 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 Southport, Kent, Liverpool and Leeds 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 fully funded one of the posts for the initial three years.

We’ll share more on the launch of each post as they are recruited.
To pay or not to pay – Avastin was the question
By Kath Fiander, whose husband was diagnosed with mesothelioma in 2016.

Malignant Pleural Mesothelioma (MPM), some words we now know intimately but not until the autumn of 2016, when like a bolt from the blue, my husband was diagnosed with the disease.

He knew where he had been exposed to asbestos when in the military. So, life for our family took on a new look, requiring hospital visits, seeking medical advice and hours on Google searching for the answer that all people in our position yearn for – the cure.

Avastin seemed to be the next best thing. So galling when a person adjacent to my husband in the chemotherapy unit received treatment. By raising funds, we can help military personnel and veterans, and signpost others, enabling patients to meet one another.

HASAG makes a difference
In the previous Mesotho 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 Lyne 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, raising money from coffee mornings and other fundraising activities to support new research, nurse recruitment, funding visits 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 CNSs across the region to prevent isolation during their illness. Its approach is holistic, ensuring that family are supported as well as the patient. HASAG was the first coffee mornings and funds others, enabling patients to meet one another.

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 disease and promote the dangers that still exist.

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

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, Cambridge, Oxford and Plymouth.

Lyne Squibb adds: “It’s vital that patients feel completely supported during their diagnosis and treatment. They need people they can trust to help them through what is a very distressing time. The support we receive and advise patients on their diagnosis and advice on clinical trials, as well as signposting patients to any other contacts such as law firms or therapists. We are also able to support Mesothelioma UK and hope that our contribution is helping to make a difference to the lives of meso patients.”

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.

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 of 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 endeavouring 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 out for more details.

Survey link: www.surveymonkey.co.uk/r/BLF_meso_survey

Groups Forum for their input and sharing of results will be analysed and shared with 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.

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Lyne Squibb adds: “It’s vital that patients feel completely supported during their diagnosis and treatment. They need people they can trust to help them through what is a very distressing time. The support we receive and advise patients on their diagnosis and advice on clinical trials, as well as signposting patients to any other contacts such as law firms or therapists. We are also able to support Mesothelioma UK and hope that our contribution is helping to make a difference to the lives of meso patients.”

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 ‘mesosisters’ 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 dampen her desires 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.”

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.
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 biobank, 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 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 patients.

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 people will have nivolumab and some will have a dummy drug (placebo) to control if nivolumab can help these people.

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.

Mesothelioma 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 AFRD 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 Roche 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 Pooja 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 MARS2’ - 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 Karen Sweeney, who describes his experience with healthcare professionals with a view to encouraging 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 Karen Sweeney.

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

Ian Toft ended the day with a brief overview of coronial matters and thanked everyone for their attendance.

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.
The International Symposium on Malignant Mesothelioma
By Meso UK Clinical Nurse Specialist and Team Leader, Lorraine Creech

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 Nurse 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 Moylan described the achievements and strategy of 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 frontline 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 biopsy, 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 Moylan 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 Defense to support research necessary to find a cure for mesothelioma. This is particularly important as the military has 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 the work of our fellow nurses. We were 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, Yvonne Bluck a classical guitarist will be playing periodically throughout but will also 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 organising and they are listed on our website. If you decide 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.

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, Yvonne Bluck a classical guitarist will be playing periodically throughout but will also play a reflective piece before the close of service when Doves will be released from the cathedral grounds and then refreshments of tea and cake will be served inside the cathedral.

Summer is here and the sun seems finally to have found his hat!! This makes us forever hopeful for those warm sunny days where we can get busy in our gardens and tend to our blooms. The Forget-Me Nots are out which always brings to mind Action Mesothelioma Day, where our thoughts are with those living with mesothelioma and those we have lost.

Marching for Meso in March was very well 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 these 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 are here and will always be here to 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@rhs.ca or contact us through our ‘Facebook’ page and leave us a message and we will get back to you, www.facebook.com/therealmesouk/

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

Jill Lemon
Fundraising & Marketing Manager
Linda Lakin - Volunteer and Patient of the Leicester MELU Luncheon Club

"On 2nd February 2017, ladies of the MELU Luncheon Club were invited and hosted for a coffee morning by the Personal Shopper team at Debenhams in the Highcross shopping centre in Leicester. We were greeted by the team and taken up into a private room where we were treated to coffee and croissants. A wonderful young man named Ed, from the Givenchy stand, carried out a make-up demonstration. He chose me as his guinea pig for the demonstration where he showed the ladies how important it was to cleanse and tone and then proceeded to give a makeup demonstration to show how we can enhance our eyes, lips and skin. Everyone commented on how much of a difference he had made and I felt just wonderful. The personal shopping team was brilliant and made us all so welcome, we played a game of lipstick bingo and we also had a competition for the best lipstick pout. The staff then did a demonstration where they modelled a group of clothes that they had put together called a Capsule Wardrobe. This was to show that picking clothes that co-ordinate can create several outfits which go from day to evening, can see a lady through a long weekend away, a special occasion, or just a week at work. Finally we were split into two groups and the Personal Shopping Team took us down into the store to help and advise us ladies with our fashion make-over. We were able to try clothes that challenged our individual tastes in a safe environment. Ed, the Cosmetics Advisor, took the other team where he helped with make up and skin care and then we were able to swap over. We all had a great time and managed to spend lots of money in the process." Linda Lakin

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

"My wonderful dad, Dermott Dougan, was born in Northern Ireland and it was true 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. Dad worked as a jenner/shop fitter throughout his career where unfortunately he was exposed to asbestos which led to his diagnosis of Mesothelioma in September 2016. A family man, dad loved spending time with mum, me, my partner Craig and our two children Tom and Sadie. Together we enjoyed lots of fun times and holidays, making lots of memories. Sadly, dad passed away peacefully at home on 19/11/17, aged just 62 years. Mum and I were at his side holding his hands as he died. We were truly amazed and overwhelmed by the amount of people in attendance at the funeral. A family man, dad loved spending time with mum, me, my partner Craig and our two children Tom and Sadie. Together we enjoyed lots of fun times and holidays, making lots of memories. Sadly, dad passed away peacefully at home on 19/11/17, aged just 62 years. Mum and I were at his side holding his hands as he died. We were truly amazed and overwhelmed by the amount of people in attendance at the funeral. We asked for donations to Mesothelioma UK in lieu of flowers and throughout the day, my family, friends and possible other family members and I have some fabulous photos to share, so far is £1,100.22 for Mesothelioma UK which will hopefully go someway to helping other families faced with this illness. Amanda Dougan., "

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 £386.86 and would like to thank all of my wonderful sponsors." Angela Tod

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

"On May 25th last year I lost a great mate and work colleague Chris Lisett to an Asbestos related terminal cancer called Mesothelioma. Mesothelioma has no cure, and it can stay in your body undetected 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 here: https://www.justgiving.com/fundraising/Anthony-Barlow2" Anthony Barlow

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

"Last year so many of you supported my climb up Kilimanjaro 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 ending a 5km run to raise more money for Mesothelioma UK by completing Buffel Last 10k. I am looking forward to this fabulous, fun filled event on the Southsea Common before my challenge and finishing with Snowdonia half marathon. I would like to thank all my dear friends and family who have so kindly supported me in 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 Giving page here: https://www.justgiving.com/fundraising/charlotte-thornton.” Charlotte Thornton

David Baugh and Phil Jackson - A Marathon for Roger Bracegirdle

"Phil and I finally signed up and there was no going back! On 2nd April 2017, we are ran, trotted and possibly even crawled the Great Manchester Marathon! Why you ask? Sadly, in the summer of 2016, my wife’s father and husband to Sue, Roger Bracegirdle, sadly passed away after a harrowing battle with cancer which was caused by working with asbestos. Mesothelioma, an aggressive cancer, is an horrific and incurable disease which devastates both the victims and families. Tragically, many working man and women went out to work in the 1950s, 60s and early 70s not knowing they were being poisoned by an illness that wouldn’t materialise until many years later. They were only trying to earn money to support their families and this is the greatest tragedy. Roger, who delivered 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 with the effects of this disease. Although many celebrities, Steve McQueen being one, have died of this horrific form of cancer there is little research into it or how to cure or slow down its process. Despite this, specialist nurses and Mesothelioma UK (the main charity) work hard to help the victims and families of this horrific disease and with the help of our supporters we managed to raise £3,471.00 so a big thank you to everyone.” David Baugh and Phil Jackson

Nic Bracegirdle - Walking for my Dad, Roger

"I took 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 £867.50. Nic Bracegirdle

June Allingan – London Marathon

"Despite having a bad throat and a heavy cold I managed to cough and splutter my way round and finished in 4:06hrs. 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 also like the one with Steve Cram wearing my running club bobble hat, and the other is where you could dance for 5 mins and earn a 53 donation from Virgin Money - so I did. Cheers all June." June Allingan

Amy Davidson & Sisters Run For Colour 2017

"Myself and my sisters are going to be taking part in this years run for colour 13+miles for Batesy! We are choosing to run for Mesothelioma UK charity because of our amazing grandad 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 for Mesothelioma UK charity and having 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" Amy Davidson & Sisters Run For Colour 2017

Kerry Cox – Walking to support my Grandfather

"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 Grandad and my Nan, going from a normal life to a full time of medication and pain. Mesothelioma is an asbestos related cancer, that many people were exposed to in 1940 right through up until 1998, 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 done and too late. Hence the reason 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 cure 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 the only cure, but unfortunately 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 Newbury for Mesothelioma UK charity and have raised £367.50." Kerry Cox – Walking to support my Grandfather
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 rears its ugly head - BANG!!! it’s too late and there is not a lot of information or awareness we had about this illness. But my dad did not get to enjoy retirement after working hard for so many years.

I have decided to take on the challenge 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 Sunday 9th April - 58 miles, then the Hero sportive on the 23rd of April - 32 miles, Iron Mountain 24th June - 40 miles, Velthon Wales 9th July - 66 miles, Llandrindod 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 you are saving for may never come. I miss my beautiful wife Annie passed away due to Pleural Mesothelioma as a result of new treatments are found. In October 2016, my beautiful wife Annie passed away due to Pleural Mesothelioma as a result of 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 teaching staff who were exposed to asbestos in the 60s, 70s and 80s.” Richard raised £2,116.77.

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. Although there was no cure for my grill had 2 to the leave the charity money in our hands.

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 Mesothelioma 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 to get our affairs in order so that’s what we do.

Another simple way to support the charity is when we or our carers plan our funeral ask for donations to Mesothelioma UK instead of flowers.

Well that’s got the more morbid things out the way so lets 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 Fundraising page to share amongst our friends and family.

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

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Richard Hoyle - Walking 100miles in a week

“In May I walked 98 miles of the Camino Way for Mesothelioma UK Charitable Trust because I 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 30 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 teaching staff who were exposed to asbestos in the 60s, 70s and 80s.” Richard raised £2,116.77.

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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 spend quality time with my family - my wife Alison and our family & friends. So I need to help find a cure for mesothelioma. 15 months on from finishing chemo, I’ll be running a 100 mile bike ride. This 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 it’s was so pleasurable 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 great dignity and positivity. I have always been so close and proud of my Dad but now even more so. He is a wonderful father and a doting Grandad (Grumps) and it is so unfair that he has been handled 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. Gerenrific! 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.

Claire Towse & Team – Paul, Mark & Clare Thompson

“My dear Dad, Alexander Richard Keewil fought a brave battle against Mesothelioma for 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 in The Nuts Challenge on the 4th March, and I’m mudly 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 Joan was exposed to Asbestos, just that it robbed us of a mother and 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 past the 26.2 miles this time but I’m sure they would be grateful for any size of donation so on the basis that “Oof” is better than “nowt here goes!” Well he did raise a wonderful £281.25.

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 siblings 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 "Oof.”

Update: “I made it to our 1 million steps for mesothelioma – in fact I busted 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.”

Why raise 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 30 years and around 2500 people a year are diagnosed.

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.

Sally Winterton

In April Sally took part in the London Marathon to raise awareness and funds for Mesothelioma UK, in what she had to say: “People get mesothelioma after being exposed to asbestos usually 20-30 years before diagnosis. It is often people who have had second-hand exposure to asbestos. Victims include people who have worked directly with asbestos but also, Handymen - from cutting the hair of factory workers, Science teachers – from working with bunsen burners, Mums and Dads, where the doctors believe it’s from having clothes washed in the same machine as grandparents when they worked in asbestos environments.

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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 stalwart 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 rain 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 & 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). It was great to have representatives from both charities to start the events, award the prizes and inform everyone about the work the charities carry out.

The runners who took part in the colour rush were Peter Olczewski, Niamh Shenouda, Natalie Zaph, Annabelle Nelson, Melkoney Harbutt, Adriana Rajka and Zanita Patolski who are part of the specialist industrial team at Boyes Turner.

The Colour Obsctacle Rush is a unique event combining the fun of colour powdered runs, the thrill of an obstacle course and the atmosphere of a music festival. The first Colour Obsctacle Rush was held in Finland in 2014 under the Finnish name “vauriotimpakuus”. The 2014 tour became the most popular obstacle run series in Scandinavia. One of our runners, Peter Olczewski said, “the run was hard work encompassing 6km of running, plenty of obstacles to haul yourself over and lots of colour thrown in to the mix, but it was well fun all the same and well worth the effort to raise money for such a great charity”.

We state the team have managed to raise a whopping £590.00 in sponsorship and donations are still coming in.

determination, energy and enthusiasm it has become a great fixture in Monmouth’s events calendar. It was also the first year that Teresa has been able to enter. The entire team at MSSC get involved in the organisation and many volunteer on the day. We all work to get involved in the local community and do something worthwhile for great causes. The times this year across all categories were excellent.

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 it 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 specialist charity.

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Cathy Fall – Brighton Marathon

“I am running my first full marathon in Brighton on 9th April 2017 to raise money for Mesothelioma UK, a registered charity offering advice and support to people suffering from this cancer caused by exposure to asbestos. This is very close to my heart as my dear Auntie Jill was cruelly taken away from us last July after being diagnosed with mesothelioma Christmas 2016. A loving, kind-hearted wife, Mum, Auntie and friend, a dedicated teacher, loved by pupils and colleagues alike; always putting others first. She was unknowingly exposed to asbestos in the schools she taught in. Experts predict that the number of school related deaths from asbestos will rise. Awareness is already increasing, but much more needs to be done to prevent this horrible life-limiting disease.” Cathy raised £911.06.

James Bennett – London Marathon

“Although I had already gained entry to 2017 London Marathon, I also want to use the opportunity to raise awareness and hopefully some money for Mesothelioma UK. Mesothelioma is a rare form of cancer generally caused by Asbestos, sadly my father passed away in 2016, due to this disease. Many cases of this Cancer are likely to occur in the coming years. It is not uncommon for the disease to take 40 years or more to develop after initial exposure to asbestos. Asbestos was used in the UK as late as the mid 1980s. Many who worked or was exposed to asbestos before this period could potentially be directly affected by this disease. The London Marathon holds many special memories for my family. My father John ran the race twice and was the inspiration for myself and my sister to also complete the race. There is no better setting to honour his memory. Hopefully with your help we can beat this disease!” James raised £1,145.49.

Amelia Ault – Enterprise Project

Amelia attends St Edwards C of E school in Castle Dorington, she is 10 years old and she is taking part in an enterprise project at school where each pupil is given a £1 and they have to increase it and say to which charity they would like the money to go. Amelia chose Mesothelioma UK in memory of Alastair Ault who was a dear family member who suffered with mesothelioma. Amelia did this off her own back without any prompting from any family members and to even know how to spell the word is just incredible!!! This is Amelia’s story of how she did it “…I was given a £1 which I spent on chocolate chips and me and my friend Alika baked some cookies to sell. We made £3.60 which she split down the middle and I then spent a £1.99 on a feather duster, I got £2 for each room that I cleaned and also an extra £1.00 for cleaning out Ozzie my ‘marshes’ cage. If I am lucky enough to win my chosen charity would be Mesothelioma UK because my uncle had cancer and the charity means a lot to me. I also do a seven and a half mile walk each year to raise money for charity and I think this too would be a very nice charity for the money to go to.”

Sarah Yorke – London Marathon

“We have attended the London Marathon to support friends in 2015 and 2016 (they both very sadly died), so in 2017, I was encouraged to enter the ballot, not thinking for one moment I would get a place on my first attempt.

However, on 13 October 2016 I did just that, I was lucky enough to get a ballot place and here we are! Unfortunately in September 2016 after months of tests and lengthy hospital stays, my father in law Richard, was diagnosed with incurable Mesothelioma (asbestos related cancer) and our family’s world was turned upside down, from the moment the diagnosis was received I knew if I were to run the London Marathon he would be my motivation.

The impact this illness has had has been devastating, but Richard (my father in law) has never stopped fighting and his mental strength, courage and determination is inspirational, as is my mother in law. So for me, this is now a very personal challenge, please support this amazing charity and help support all those that have been and will be affected by Mesothelioma.”

Sarah raised £22,791.25 which included a very generous donation of £20,000 from Christine Brown of Brown Solicitors.
Aly McCann – Held a Funfair 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.


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 mum.

Mary Law – Bluebell Ball at the British Legion, Lower Bormal, 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 £62.55 from their collection pots.

Transmac ingraham Services Ltd – held a Casual Dress Day on Friday March 19th and raised £850.00 and the Book People kindly donated £470 to Transmac making the overall total raised £374.70.

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

Murray Park Community School – raised £110.00 in support of Sam Peace’s 10 marathons in 10 days bringing the overall total that Sam raised to an amazing £694.00.

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

Barbara Heslop – Chopwell Drama Group held a recent production in memory of her husband Dave who had been a member for thirty years and raised £58.00.

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The Mesothelioma UK Charitable Trust exists to raise funds to support the services provided by Mesothelioma UK and any sponsorship, grants or donations made to the charity support this.

Mesothelioma UK Charitable Trust would like to thank all of our wonderful donors.

If you would like to find out more about becoming a Corporate Partner or Friend, contact our Fundraising Manager Jill Lemon on 0800 169 2409.

Gold Donors 2017/18

Silver Donors 2017/18

Bronze Donors 2017/18

Corporate Partners

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 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 of Snowdon. 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

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