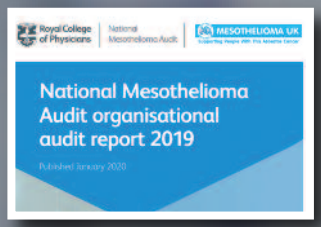
MESOTHELIOMA MATTERS

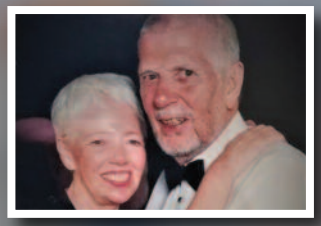
Spring 2020

Developments in clinical trials

MP introduced to Armed Forces project



Organisational Audit results



David Nurse golfs for Meso UK

MESOTHELIOMA UK
Supporting People With This Asbestos Cancer

LEGAL DEFINITION OF TERMINAL ILLNESS

The All-Party Parliamentary Group (APPG) for Terminal Illness raises awareness of issues around terminal illness in Parliament. The APPG for Terminal Illness has written a report following its inquiry into the impact of the legal definition of terminal illness on access to benefits for people living with terminal conditions.

Published in July 2019, the report contains the findings from this inquiry and gives recommendations to policy makers on ways to improve the legal definition and guidance to healthcare professionals.

The report includes a foreword from Drew Hendry MP who set up the APPG for Terminal Illness: "People who are living with the devastating impact of a terminal diagnosis should, at the very least, be able to expect quick and easy access to the support they need. The APPG for Terminal Illness believes that there is no evidence-based reason why the UK Government cannot follow the Scottish Government and allow medical professionals to certify that a person is terminally ill, entitling them to fast-track access to benefits, with no arbitrary and outdated time limit."

We've added a link to the report to the Benefits and Compensation page of our website at www.mesothelioma.uk.com

PERITONEAL MESO EVENT

Our dedicated peritoneal mesothelioma nurse, Sam Westbrook, has organised an event for those affected specifically by this type of mesothelioma.

The free day is an opportunity to ask healthcare professionals questions and to meet others in similar situations. There will also be talks about the disease, oncological treatments, when to operate, psychological wellbeing and nutrition.

The Peritoneal Mesothelioma event, sponsored by HASAG, takes place from 10-4pm on Friday 24 April at the Apollo Hotel, Basingstoke. Visit www.eventbrite.co.uk and search 'Peritoneal mesothelioma' to book tickets.

MESO UK RESEARCH SHOWN AT INTERNATIONAL CONFERENCE

iMig2020
MARCH 25 - 28, 2020
BRISBANE, AUSTRALIA
www.iMig2020.org

The International Mesothelioma Interest Group conference (iMIG) is a multidisciplinary meeting that brings together over 500 delegates from around the world. It features the most up-to-date research, diverse topics of interest and educational sessions with leading experts.

This year, several Mesothelioma UK nurses have been invited to exhibit their research studies, demonstrating the high calibre of their work.

Author: Louise Gilham
Study title: An audit to explore if the number of patients with mesothelioma reported through the Cancer Data Set correlate with the number of patients diagnosed within Kent

Study title: An audit to explore the demographics of patients diagnosed within Kent

Author: Sam Westbrook
Study title: Achieving Equity in Treatment and Support for Peritoneal Mesothelioma: Establishing the UK National Peritoneal Mesothelioma Multi-Disciplinary Team

Study title: Clarifying diagnosis and surgical selection in 155 patients with peritoneal mesothelioma; early oncologic outcomes from a monthly video-conferencing national multi-disciplinary team meeting

Authors: Simon Bolton, Jennifer Seavor, Royds Withy King and JP Swoboda, 12 Kings Bench Walk
Study title: Non NHS funded therapy v clinical trials: the importance of patient autonomy in mesothelioma treatment decision making

Authors: Simon Bolton, Maria Guerin
Study title: Development of Mesothelioma Care Passport

Author: Anne Moylan
Study title: Evaluation of Mesothelioma in a Large District General Hospital in the UK 2017 - 2018. A Retrospective Case Note Audit

Author: Liz Darlison
Study title: Patient Experiences in the MARS 2 Study

Authors: Liz Darlison, Angela Tod, Stephanie Ejegi-Memeh, Virginia Sherborne
Study title: Impact and inequalities: findings from the Military Experiences of Mesothelioma Study (MiMES)

Authors: Virginia Sherborne, Angela Tod, Jane Seymour, Liz Darlison, Anne Moylan
Study title: The psychological effects of mesothelioma on patients and carers: a scoping review

Authors: Stephanie Ejegi-Memeh, Michaela Senek, Angela Tod, Steve Robertson, Liz Darlison
Study title: Gendered experiences of asbestos exposure, mesothelioma risk and pursuing a civil compensation claim

Authors: Michaela Senek, Angela Tod, Steve Robertson, Stephanie Ejegi-Memeh, Liz Darlison
Study title: Sex-differences and gendered experiences in mesothelioma: analysis of Asbestos Support Group data in England

Author: Simon Bolton
Study title: Exploring the barriers faced by mesothelioma patients when accessing clinical trials in the UK

It's an honour for the nurses to have the opportunity to share their work with mesothelioma experts from around the world. This is an opportunity to show international colleagues some of the important research work that Mesothelioma UK funds and carries out.

MIMES STUDY UPDATE

Mesothelioma UK is currently funding a PhD student, Virginia Sherborne at the University of Sheffield. Her research project is part of the university's Military Mesothelioma Experience Study, known as MiMES.

In January 2020, Virginia successfully passed her Confirmation Review, a progress report and panel review of work-to-date by university academics, which is required for PhD students to progress with their studies.

The next stage of the project is for Virginia to prepare her literature review for publication and to apply for Research Ethics, giving her permission to commence recruiting and interviewing participants.

As a qualified counsellor with a special interest in trauma and bereavement, Virginia has chosen to focus her study on the psychological effects of mesothelioma in UK military veterans, looked at from the carer's perspective.

THE ROLE OF MESOTHELIOMA UK CLINICAL NURSE SPECIALISTS IN PALLIATIVE CARE NEEDS

Mesothelioma UK is funding a new study being carried out by Dr Clare Gardiner, Professor Angela Tod, and Professor Jane Seymour from the Division of Nursing & Midwifery at the University of Sheffield.

Dr Gardiner commented: "Whilst we are continually striving to find better treatments for mesothelioma, many patients and their families will require palliative care. However, we know little about the palliative care needs of patients with mesothelioma and their families. An important innovation in this field is the introduction of the Mesothelioma UK clinical nurse specialist.

"These highly trained and specialist nurses provide a crucial role in supporting patients towards the end of life, yet their role in providing palliative care is under-researched. The aim of our research is to explore the palliative care needs of patients with mesothelioma and assess the diverse ways in which Mesothelioma UK clinical nurse specialists are helping to support and empower patients with palliative care needs and their families.

"We will use a mixed methods research design including analysing data from the National Mesothelioma Experience Survey (2012) and the more recent Mesothelioma Outcomes Research & Experience (MORE) survey. We will also undertake qualitative focus groups with Mesothelioma UK clinical nurse specialists to explore their role in the provision of palliative care. We hope that this research will contribute to better understandings of the care and support that people with mesothelioma need towards the end of life and establish the important role of Mesothelioma UK clinical nurse specialists in meeting these needs."

The study is due to begin in April 2020. For more details, please contact Dr Clare Gardiner at c.gardiner@sheffield.ac.uk

NEWS FROM THE NATIONAL CENTRE FOR MESOTHELIOMA RESEARCH

The last few years at the National Centre for Mesothelioma Research (NCMR) at Imperial College London have been productive. One of the Centre's main areas of focus is using genomics to look at the basic biology of mesothelioma and finding clues in the cancer DNA for potential therapies.

The NCMR has now made public its results from the last three years of research. These findings have not yet been peer-reviewed by independent experts and must be considered as provisional. However, the researchers have discovered previously undetected stretches of DNA that are either deleted or amplified in mesothelioma tumours. These DNA changes affect important pathways that may be amenable to therapy and the NCMR team have found several drugs that strongly inhibited the growth of mesothelioma cells. It also found unexpected clues to making immunotherapy more effective.

Professor Bill Cookson, Director of the NCMR, said: "We are encouraged by these results that seem to suggest a number of ways in which mesothelioma may be treated. However, giving drugs to cells in test tubes is very different to giving the same drugs to patients, and there is a huge challenge ahead in organising funding and interest from pharmaceutical companies that will be needed for clinical trials."

Miriam Moffatt, Deputy Director of NCMR said: "It is very gratifying how scientists and doctors in different institutions in the UK and Canada have worked so effectively to get these results. We realise that we owe it to patients with the disease to push on now, as quickly as we can."

You can read more about the NCMR on the Centre's website at www.imperial.ac.uk/ncmr

THE BRITISH LUNG FOUNDATION'S MESOTHELIOMA RESEARCH UPDATE

The Mesothelioma Research Network (MRN) is designed to bring researchers in the field together to share knowledge, skills and resources. It aims to drive research progress for patient benefit by encouraging collaboration and increasing the funding invested in mesothelioma research. Now 180 MRN members worldwide have joined.

As a result of the generous £5 million donation from the Victor Dahdaleh Foundation to set up the MRN and to support the Mesothelioma Stratified therapy (MiST) trial and MesobanK through BLF grants, a further £24.57 million funding has been leveraged back into mesothelioma research. In 2019, 12 new collaborations or potential collaborations have formed as a result of the MRN being in place, adding to the three collaborations already started.

The MRN has recently awarded £10,000 of funding to members to travel to the International Mesothelioma Interest Group (iMig) meeting 2020 in Brisbane. The call for applications for the second-ever BLF MRN collaborative pump-priming research grant has just closed, and it will be awarding this £40,000 grant in summer 2020.

It is planning the MRN Research Day 2020 on Monday 29 June in Birmingham. The meeting will showcase the latest research and allow MRN members to network. This meeting is complemented by MRN webinars, which allow sharing of knowledge between our members.

If you work in mesothelioma research, join us: www.blf.org.uk/mrn

UKATA DONATES £5,000 TO MESOTHELIOMA UK

With the UK having the highest mortality rate from lung disease in Europe, a decision was made during 2018 – 2019 for the UK Asbestos Training Association 'UKATA' to become corporate donors to Mesothelioma UK.

The aim of the partnership was to support the charity and to improve care and treatment for all UK mesothelioma patients and carers.

With the support from UKATA members, who provide approved asbestos training nationwide, the association was able to raise £5,000 to support people living with asbestos-related cancer.

AVSGF UPDATE - CALLING FOR EQUALITY

By Joanne Gordon, Chair of the Asbestos Victims Support Groups' Forum and Graham Dring, Retiring Chair of GMAVSG

Partners and dependents of victims of mesothelioma who have been unable to claim government compensation in-life are being treated unfairly, according to the Asbestos Victims Support Groups' Forum. The Forum is campaigning for equalisation of government schemes for posthumous and in-life claims.

The case for equality

Support groups throughout the country help victims of mesothelioma to claim benefits and government compensation. The Pneumoconiosis etc (Workers' Compensation) Act 1979 and the 2008 Diffuse Mesothelioma Scheme provide compensation for victims who cannot make a legal claim. This is fair and just.

However, there is an inconsistency in the schemes. If applications are made after the patient has died, the payments, which can only be claimed by surviving partners or dependent children, are substantially lower.

A victim, aged 77, making a claim based on a 100% IIDB award will receive £14,334. The surviving partner of someone who passed away at the age of 77 will receive £7,949. Family members feel that their loved one's life (after death) is of less value.

This is surely morally wrong, especially as in a legal claim, a surviving partner will suffer no such disadvantage.

To add insult to this already unfair situation, victims' families could suffer a financial hardship as people budget on the basis of two incomes and through no fault of their own, they are reduced to one income and further disadvantaged by receiving a lower government compensation payment.

The victims who receive payments are not interested in the money for themselves. However, they are concerned about the financial security of their families. In this situation, there is clearly a moral and financial case for equalising the level of posthumous payments.

The Campaign

The Forum is campaigning for equality of payments. Victims and their families have sent hundreds of postcards to their MPs calling for equality. In 2010, the Government acknowledged that there was no justification for differential payments, acknowledging that such inequality could add additional anxiety at a time when they are most vulnerable. Therefore, bridging the gap is long overdue. The schemes will soon be debated in Parliament and we are urging MPs to call for equalisation.

Contact Asbestos Victims Support Groups' Forum:
T: 01246 380415
Web: www.asbestosforum.org.uk
Twitter: @AsbestosForum

CLINICAL AND SURGICAL OUTCOMES OF PATIENTS WITH PERITONEAL MESOTHELIOMA

Peritoneal mesothelioma (PM) is a rare primary neoplasm of the peritoneum with an increasing incidence worldwide. A national PM multidisciplinary team (national PM MDT) video-conference meeting was established in the UK and Ireland in March 2016, aiming to plan optimal treatment, record outcomes and provide evidence for the benefits of centralisation.

Between March 2016 and December 2018, patients with PM, referred to peritoneal malignancy centres in Basingstoke, Birmingham, Manchester and Dublin, were discussed by the national PM MDT via video-conference. The MDT was composed of surgeons, radiologists, specialist nurses and pathologists. Patients were considered for cytoreductive surgery (CRS) and hyperthermic intraperitoneal chemotherapy (HIPEC) if considered fit for surgery and if radiological imaging suggested that complete surgical cytoreduction could be achieved. Morbidity and mortality following surgery were analysed. Survival analysis following MDT discussion was conducted.

A total of 155 patients (M:F ratio 0.96) with an average age of 57 years were discussed. To date, 22 (14.2 per cent) have had CRS and HIPEC; the median Peritoneal Cancer Index for the surgical group was 17.0. Complete cytoreduction was achieved in 19 patients. Clavien–Dindo grade I–II complications occurred in 16 patients; there was no grade III–IV morbidity or 30-day in-hospital mortality. The median follow-up for the whole cohort was 18.7 months, and the 2-year survival rate from time of first review at the national PM MDT was 68.3 per cent.

The centralised national PM MDT was effective at selecting patients suitable for CRS and HIPEC, reporting a good outcome from patient selection.

To download a full copy of the report, visit https://bjssjournals.onlinelibrary.wiley.com/doi/10.1002/bjs5.50256

NEW MESOTHELIOMA RESEARCH PUBLICATIONS

Mesothelioma UK is delighted to include this new, regular addition to Mesothelioma Matters. In each edition, any new publications in the preceding three months, the title, author and journal, will be listed. We hope that you find this useful and thank you to University Hospitals of Leicester (UHL) clinical librarians!

New scientific research
Diagnosis of Mesothelioma.
Author(s): Fels, Elliott et al
Source: Surgical pathology clinics; Mar 2020; vol. 13 (no.1); p. 73-89

Malignant mesothelioma in situ: morphologic features and clinical outcome.
Author(s): Churg, Andrew et al
Source: Modern pathology: an official journal of the United States and Canadian Academy of Pathology, Inc; Feb 2020; vol. 33 (no.2); p. 297-302

Localized malignant mesothelioma, an unusual and poorly characterized neoplasm of serosal origin: best current evidence from the literature and the International Mesothelioma Panel.
Author(s): Marchevsky, Alberto et al
Source: Modern pathology: an official journal of the United States and Canadian Academy of Pathology, Inc; Feb 2020; vol. 33 (no.2); p. 281-296

Malignant Peritoneal Mesothelioma: Patterns of Care and Survival in The Netherlands. A Population Based Study
Author(s): de Boer N.L. et al
Source: European Journal of Surgical Oncology; Feb 2020; vol. 46 (no.2)

Mesothelioma Associated With the Use of Cosmetic Talc.
Author(s): Moline, Jacqueline et al
Source: Journal of Occupational & Environmental Medicine; Jan 2020; vol. 62 (no.1); p. 11-17

Responses to this paper: Evidence Does Not Support Exposure to Cosmetic Talc as Cause of Malignant Mesothelioma.
Author(s): Geyer, Stanley J et al
Source: Journal of occupational and environmental medicine; Feb 2020; vol. 62 (no.2); p. e83

Authors' Response to "Evidence Does Not Support Exposure to Cosmetic Talc as a Cause of Malignant Mesothelioma".
Author(s): Moline, Jacqueline et al
Source: Journal of occupational and environmental medicine; Feb 2020; vol. 62 (no.2); p. e85

Diagnostic Value of Computed Tomography Imaging Features in Malignant Pleural Mesothelioma.
Author(s): Fortin, Marc et al
Source: Respiration; Jan 2020; vol. 99 (no.1); p. 28-34

Tumour Treating Fields in combination with pemetrexed and cisplatin or carboplatin as first-line treatment for unresectable malignant pleural mesothelioma (STELLAR): a multicentre, single-arm phase 2 trial
Author(s): Ceresoli G.L. et al
Source: The Lancet Oncology; Dec 2019; vol. 20 (no.12); p. 1702-1709

Responses to this paper: Tumour Treating Fields for mesothelioma - Authors' reply
Author(s): Ceresoli G.L. et al
Source: The Lancet Oncology; Jan 2020; vol. 21 (no.1)

Qualitative studies and patient experience
A survey of patient and caregiver experience with malignant pleural mesothelioma.
Author(s): Warby, Anne et al
Source: Supportive Care in Cancer; Dec 2019; vol. 27 (no.12); p. 4675-4686

Responses to a cancer diagnosis: a qualitative patient-centred interview study
Author(s): Kirby E.R. et al
Source: Supportive Care in Cancer; Jan 2020; vol. 28 (no.1); p. 229-238

Please contact your own clinical library or view the journals webpages to seek access to the full publications. To have details of any new publications listed in the next edition of Mesothelioma Matters, please send information to meso@sandstarcomms.com

UHL Clinical Librarian Service
"bringing you the evidence"

YOUR QUESTIONS ANSWERED

This is the first in a regular series of Q&As where our clinical and benefits experts will answer some of your burning questions.

Should I spend my savings on treatment that I can't get on the NHS?
Mesothelioma UK would urge you to talk to your clinical team or contact Mesothelioma UK to discuss your particular circumstances. The reason that treatments are not available on the NHS is generally because there is not large-scale randomised trial evidence available to support their approval.

Many of the novel treatments patients are interested in are available in clinical trials and accessing them this way is far more preferable. This might require you to visit an NHS centre some distance from where you live but the treatment would be free and in addition, you will have the full support of an expert team. If the trial team are not able to offer you clinical trial entry, they may well discuss treatment options not available on the NHS. It might be possible to access some treatment options via a compassionate use system which means that the drug company supply the drug free, sometimes in return for being able to monitor you while you receive the treatment.

Occasionally, some patients do not meet clinical trial entry criteria and so other treatments outside of the NHS might be considered. For these, a cost would be incurred. This should only be considered when all other proven or clinical trial options have been exhausted. Mesothelioma UK would urge you to explore non-NHS treatments with a clinical team fully aware of all clinical trial options and it is likely it would be a different clinician who provides non-NHS treatment. If you have a civil claim, please ensure that your lawyer is aware that you want potential non-NHS / non-trial treatment costs to be included in your civil claim.

If in doubt, ring Mesothelioma UK's information line and chat things through with one of the charity's expert nurses.

I am ex-RAF. I was exposed to asbestos during my RAF service and again as a civilian. How does this affect my benefit and compensation entitlements?
This would be classed as a dual exposure so you would be entitled to apply for a lump sum of £140,000 from your time served in the Armed Forces, and then apply for industrial injuries benefits from the DWP. We would recommend that you speak to a specialist mesothelioma solicitor to look at the possibility of pursuing compensation. If you are successful in a civil compensation claim, the £140,000 would be paid back to the MoD and the remainder paid to you. Attendance Allowance and Blue Badge would also be applied for.

I really want to explore the possibility of having surgery for my mesothelioma but it isn't available locally to me. How can I get to see a surgeon?
Radical surgery for mesothelioma where all visible disease is removed is called Extended Pleurectomy Decortication or EPD for short. This type of surgery is currently the subject of a large randomised trial called MARS 2. Results from this trial will hopefully provide the evidence needed to tell us if EPD surgery should be made widely available throughout the NHS. Until then, this type of surgery is generally only available within a hospital involved in the MARS 2 study.

To assess your eligibility, your circumstances will have been discussed at a Multi-Disciplinary Team (MDT) meeting. This is likely to be a lung cancer MDT but there are an increasing number of mesothelioma specific MDTs too. Whichever, at that meeting they would have staged your mesothelioma and if eligible for MARS 2, the option of being referred to a surgeon involved in the study should have been offered. Please discuss this with your local clinical team or as always, contact the Mesothelioma UK information line where one of our expert nurses will be glad to talk to you.

If you have a question that you want answered by Mesothelioma UK experts, please email meso@sandstarcomms.com

NEW GRANT OPPORTUNITIES WITH RCLCF

Mesothelioma UK continues to make funding available for research with two new grant opportunities now available in collaboration with the Roy Castle Lung Cancer Foundation (RCLCF).

The two grants will support innovative research into mesothelioma cancer in the areas of patient experience and palliative care/symptom control.

For Patient Experience studies
Applicants from professionals, such as nurses and allied healthcare professionals who are either involved in the patient experience of mesothelioma or have experience of conducting research into patient experience which can be applied to this group of patients. This grant will not exceed 12 months duration and a maximum of £25,000 may be applied for.

Palliative care/symptom control studies
Applicants from professionals who have a specific clinical interest in palliative care/symptom control of patients with mesothelioma. This grant will not exceed 24 months duration and will not exceed £50,000 per annum.

Applications should be made via the RCLCF website at www.roycastle.org/research/research-grants

EARLY OUTCOMES FROM THE MACMILLAN SCOTTISH MESOTHELIOMA NETWORK

Following the successful development of the West of Scotland Mesothelioma MDT in 2012 and in response to inequality in the provision of mesothelioma services across Scotland, the Macmillan Scottish Mesothelioma Network was launched in April 2019. The network was funded by a consortium of partners including Macmillan Cancer Support, Mesothelioma UK and NHS Greater Glasgow & Clyde.

The network funds sessional time for Lead Clinicians, Clinical Nurse Specialists and administrative support in Glasgow, Edinburgh, Dundee, Aberdeen and Inverness, and coordinates a weekly video-linked MDT meeting involving all sites. MDT members are also funded and represent all relevant specialties. The aim of the network is the provision of consistent high-quality care and equitable access to clinical trials for all patients.

The MDT has retrospectively reviewed national MDT activity over the first seven months of operations.

Information on all cases referred to the 27 MDT meetings held between 12/4/19 and 25/10/19 were reviewed retrospectively, using MDT documentation and electronic records. Patient demographics, procedural data and diagnostic findings (imaging, pathology (including BAP1 immuno-histochemistry (IHC), molecular pathology (including P16 fluorescence in-situ hybridisation (FISH)) were all available. Treatment recommendations including clinical trial eligibility and subsequent recruitment were also recorded.

132 patients from 21 individual Scottish hospitals were referred, prompting 187 case discussions. 88% (n=116) were male. The median age was 72 years. 80/132 (61%) patients described prior asbestos exposure. ECOG performance status was recorded in 94% (PS 0 in 17%, 1 in 53%, 2 in 14%, 3 in 8%, 4 in 2%).

125/132 (95%) had an attempt at histological sampling, which was definitive in 116/132 (88%) patients, using the following methods: Surgical Thoracoscopy (41%, n=48), Local Anaesthetic Thoracoscopy (26%, n=31), image-guided biopsy (29%, n=34), Abram's biopsy (1.7%, n=2), unrecorded in 8%, n=10. Standard histological assessment was supplemented by BAP1 IHC +/- P16 FISH in at least 14/132 (11%) patients (based solely on data recorded on MDT forms).

109/132 cases were diagnosed with mesothelioma, of the following sub-types: Epithelioid (66%, n=77), Biphasic (15%, n=17), Sarcomatoid (9%, n=10), Desmoplastic (3%, n=3), Undifferentiated (2%, n=2). Disease stage was recorded in 87/109 (74%) cases, and was Stage I in 39%, Stage II in 11%, Stage III in 22%, Stage IV in 8%). 7/109 (6%) patients had Peritoneal Mesothelioma.

Clinical trials including MARS 2, CONFIRM, ATOMIC-Meso, INITIATE, SYSTEMS2 and Meso-TRAP were recommended in 58/132 (44%) patients. Of these, 14/58 (24%) patients were recruited, most frequently to MARS 2. This represents 13% of the mesothelioma population. A palliative care specialist was present for 23/27 (85%) MDT meetings, facilitating direct palliative care referral in 27/132 (20%) patients.

This review demonstrates the value of a fully-funded national clinical network and associated MDT. Over the first seven months of operation, the network has provided high quality diagnostic services and a consistent approach to therapeutic options, based on international guidelines. Ensuring equitable access to a broad portfolio of clinical trials will remain a major priority. More comprehensive recording of staging information is required.

IS YOUR CURRENT LEVEL OF ASBESTOS MANAGEMENT IMPACTFUL?

There are many solutions to achieving effective asbestos risk management and choosing the correct solution is vital to making your system work. Lucion Services will be presenting new knowledge and best practices at its annual conference, Asbestos The Truth on 14 May 2020.

2020 will mark the tenth anniversary of the Asbestos The Truth Conference. Asbestos Risk Management Consultants, National Asbestos Contract Managers and Lucion Services Directors will be providing delegates with the tools to implement an effective asbestos management system. Moving away from exploring the reasons why duty holders should manage their asbestos risks, this year, the conference will focus on not only how to manage asbestos but how to give your asbestos management activities impact through implementing best practices.

Visit www.asbestosthetruth.com to secure your tickets.

Asbestos: The Truth
Asbestos Management Conference 2020

MY PLEURAL EFFUSION JOURNEY

Dr Matthew Evison, Wythenshawe Hospital, Manchester University NHS Foundation Trust
Dr Deepan Sivakumar, Guys' and St Thomas' NHS Foundation Trust
Dr Rahul Bhatnagar, North Bristol NHS Trust

A malignant pleural effusion is a build-up of fluid around the lung that is caused by cancer. This can be a complication of any cancer but particularly affects patients with mesothelioma, lung cancer and breast cancer. There is normally a thin film of fluid between the lung and rib cage but, for a number of different reasons, cancer can cause an excess of fluid to build up. This can cause a number of symptoms but particularly breathlessness which can be very troublesome and disabling.

There are various procedures that can help drain this fluid away and sometimes stop it from coming back again. No one procedure has been shown to be dramatically superior to another and patient choice is critical in making the right decision. The different approaches to managing the fluid affect how much time is required to be spent in hospital, how much aftercare is required and how likely it is that a repeat procedure might be needed. There are also certain circumstances where doctors may recommend one procedure over others, but the reasons behind this are usually complex.

Therefore, a team of chest specialists from Wythenshawe Hospital (part of Manchester University NHS Foundation trust), Southmead Hospital (North Bristol NHS Trust), Guy's & St Thomas' NHS Foundation Trust and Oxford University Hospitals NHS Trust set out to develop a patient information resource and decision aid to help those affected with a malignant pleural effusion. The project was funded by the North West Lung Centre Charity with additional support provided by the Avon Mesothelioma Foundation.

The content was co-produced with patients, carers and clinicians in three local focus groups in Manchester, Bristol and London, followed by one national focus group.

This process of content development in the focus groups was facilitated by experts at the National Institute of Health Research Collaborations for Leadership in Applied Health Research and Care (NIHR CLAHRC) Yorkshire and Humber Team, led by Professor Angela Tod.

The project team paired with One Vision Health, a medical web design agency, to develop the online platform and produce short animations to help explain complex medical problems and treatments.

Visitors to the website will be able to learn about:

- What is a pleural effusion
- What is a malignant pleural effusion
- What are the different ways of managing a pleural effusion
- What might be a person's priorities when it comes to deciding on one of these treatment options, potentially helping with discussions in clinic

Users will have the opportunity to provide feedback on the website and become part of the My Pleural Effusion Journey Team. We want to continue the co-development of this project and adapt to the feedback and experiences of patients, carers and clinicians to develop this platform further in the future.

We truly hope this will be a valuable tool for anyone affected by this troubling condition who wishes to know more, and that it helps them to understand what treatments are available and how they might fit in with their own preferences and priorities.

www.mypleuraleffusionjourney.com

ASBESTOS IN SCHOOLS CAMPAIGN

By John McLean, Chair of Joint Union Asbestos Committee (JUAC)

In 2000, Gina Lees, a 51-year-old schoolteacher, was diagnosed with mesothelioma and passed away soon after. Understandably, her husband Michael was devasted and like many other family members before and since, was completely in the dark about how and why his beloved wife had died from exposure to an industrial material, asbestos, that he knew very little about.

Michael then embarked on a 15-year campaign to understand more about asbestos exposure in schools and raise public awareness of this serious issue. He turned initially to the National Union of Teachers (NUT) - now the NEU - for assistance. As he became more involved, others including trade unions, lawyers, victim support groups and even politicians came on board and started to make waves in government circles.

In 2009, I was the National Health and Safety officer for the GMB trade union which had a long history of involvement in asbestos issues, principally due to the workers represented in many industries where asbestos featured. Along with the other educational support trade unions, Unison and Unite, we became involved in the campaign. The difficulty that the Asbestos in Schools (AiS) campaign had was that outside of Michael's diligence and enthusiasm, the campaign is largely an ad hoc conglomeration of individuals and differing groups.

In 2010, the education trade unions decided to set up, with Michael's endorsement, the Joint Union Asbestos Committee (JUAC) which had officers dedicated to health and safety concerns of the members and could hopefully dedicate greater resources to the campaign. Upon my retirement from GMB in 2015, I became chair of JUAC and also took on the coordinating role for AiS from Michael who deservedly stood down.

The scale of the problem

From the ruins of the Second World War and the building of 'homes fit for heroes', the establishment of the NHS and the need for the new medical facilities, to the baby boom of the 1950s and 1960s which necessitated the need for more schools, the common feature they all had was the extensive use of the 'magic mineral' – asbestos. No one at the time recorded how much asbestos was being used in this new build and perhaps more importantly, where it was used.

Many of these buildings right across the public sector are still in use, perhaps partially refurbished or rebuilt, but substantially little altered in the fabric of the building and still containing asbestos after 50 plus years. As well as ignorance of the actual amount of asbestos used (unless regular monitoring on the condition of asbestos in buildings takes place), as assumed by the control of asbestos at work regulations, then the potential for exposure to asbestos fibres remains largely unknown.

It is estimated that over 80% of schools across the UK contain some asbestos. Part of our ongoing campaign has been to establish a database on asbestos in schools, regarding its presence and condition. Over the last two years, the Department for Education (DfE) has been carrying out an Asbestos Management Assurance Programme (AMAP) in an attempt to gather information relating to asbestos in each school. However, this was not a mandatory survey on schools as this was felt to increase burdens on school leaders already under pressure on other aspects of school leadership.

The exercise was extended twice as first responses were relatively poor and the results were published in a more limited form than we had hoped in the summer of 2019. It was clear from these results that assumed figures of over 80% of the schools across the UK did contain at least some asbestos. Around 83% of schools responded, which while a positive figure, meant that 17% of schools had not responded. It is not clear if this was due to the non-mandatory nature of the exercise, ignorance of the duty holder, responsibilities in respect of asbestos management or a lack of clarity on who exactly has the duty holder role. Some of this may be due to the fracturing of the school estate over the last ten years, with the growth of academies and the lessening role for local authorities, many of whom have lost local knowledge and asbestos expertise.

Has anything of significance been achieved?

It sometimes feels with the passage of time that little positive change has occurred. Some of the aims of the campaign including the phased removal of asbestos on a priority basis, have not happened. However, the collaboration of central data to establish the scale of the asbestos problem has, in an albeit limited manner, begun and we would look to build on this. In addition, at the beginning of the coalition Government, resources and

expertise were stripped from the Health & Safety Executive (HSE) which allied to a downgrading of the education sector to a low priority sector, resulting in a no proactive inspection regime from the HSE, even though it was clear that a large number of schools contained asbestos.

As another objective of the campaign is to restore these inspections, we were pleased to see that the establishment of two pilot inspection schemes from the HSE including the targeting of those schools that either had not responded to the AMAP survey, or where it is clear that asbestos management is inadequate. Following this, the public profile of asbestos in schools has also risen, although it seems that the public and media's attention span is limited. Also, following discussions with the trade unions, better guidance for the management of asbestos is being devised.

The future?

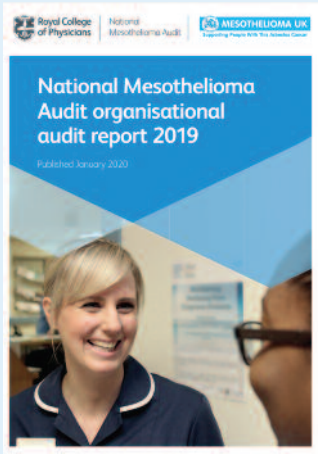
It is pointless only blaming the current administration for the problems of asbestos in schools as successive governments have 'kicked the can down the road' in terms of making major decisions on areas such as the phased removal of asbestos on a priority basis.

The asbestos in schools is often over half a century old and with weathering and a workplace that is not normal in the sense that children do not behave as adults but run, push, bump and make holes in walls with pens. In addition, the Government's own committee on carcinogenicity has stated that as children's lungs are not fully developed, they are more susceptible to asbestos-related diseases following fibre exposure.

With the loss of those heavy industry jobs as formerly represented by GMB, it is acknowledged that the future asbestos exposure will come from the 'built environment', such as schools and hospitals in the future. One other obvious note is that by putting off a comprehensive plan for dealing with the problem, any costs associated with its future removal will only increase and it would be eminently sensible to cost and plan for this very expensive undertaking.

In terms of the campaign, there really is no alternative but to carry on despite setbacks and often ignorance in either those with responsibility not knowing (or not wanting to know) the scale of the problem. As those in the meso world are only too aware, we just don't have the option to give up!

UK'S FIRST MESO ORGANISATIONAL AUDIT



A new report from the Royal College of Physicians (RCP) and Mesothelioma UK shows that asbestos-related cancer patients who were referred to a specialist mesothelioma multidisciplinary team (MDT) in the UK were significantly more likely to benefit from access to a mesothelioma-specific clinical nurse specialist and on-site access to mesothelioma clinical trials.

The National Mesothelioma Audit organisational audit report 2019 was produced by the Royal College of Physicians and funded by Mesothelioma UK. The audit was commissioned to obtain an accurate and up-to-date picture of mesothelioma multidisciplinary team (MDT) services across the UK, and to identify any variation in access to specialist services and treatments for mesothelioma patients.

All known lung MDTs (174) across England, Wales, Scotland and Northern Ireland were invited to take part in the audit, of which 125 (72%) MDTs actively participated in the study.

Variation was identified across all participating MDTs in the access to services offered to mesothelioma patients. Overall, 17 mesothelioma MDTs self-identified as providing specialist mesothelioma services, managing over 25 new cases per year.

Comparing service provision across all participating MDTs, patients who were referred to one of the 17 specialist mesothelioma MDTs appeared more likely to benefit from access to a mesothelioma-specific clinical nurse specialist 53% (9/17) vs 14% (18/125) and on-site access to mesothelioma clinical trials 88% (15/17) vs 33% (40/121).

The full report can be downloaded from www.rcplondon.ac.uk/projects/outputs/mesothelioma-organisational-audit-2019

THE CHANGING FACE OF ASBESTOS

By Louise Larkin, senior asbestos lawyer at Thompsons Solicitors, discusses the wide-reaching impacts of asbestos use in the UK

Gone is the misconception that asbestos disease only affects men who worked in factories or industry. Thompsons Solicitors is still seeing the impact that the substance is having on a wide spread of ages and professions.

Mesothelioma death rates have increased more than ten-fold since the late 1960s, when official recording into the British Mesothelioma Register began. According to the Health and Safety Executive (HSE), mesothelioma has claimed the lives of 49,823 men and 8,896 women between 1981 and 2017 – now reaching 2,500 deaths per year – many as a result of exposure to asbestos decades before. Women now account for approximately one in six mesothelioma deaths in the UK.

The law recognised the serious health risk posed by asbestos within public buildings such as schools, hospitals and libraries. An explicit duty was introduced for owners of non-domestic properties to find out whether their premises contained asbestos, assess the risks and act proactively to manage them. However, evidence shows that this is not happening and people are still being put at risk.

A recent Freedom of Information request revealed that a staggering 198 out of 211 NHS Trusts have asbestos in their buildings. Meanwhile, schools have been referred to the national health and safety body over concerns they are failing to safely manage asbestos in their buildings, where it is noted that approximately 319 teachers have died of mesothelioma.

I have had the privilege of representing a number of people who have been exposed to asbestos in public buildings, such as former nurse Sandra Kellett, who was exposed during hospital ward refurbishments in the 1970s. More recently, I successfully pursued a case against Liverpool City Council on behalf of the family of David Trimm, who was exposed to asbestos as a pupil at a secondary school in the late 1970s and later died from the disease, aged only 53.

Thompsons Solicitors works hard to support various campaigns with unions and asbestos groups to raise awareness of the risk of asbestos exposure in public buildings. It is vital that plans are put in place to control and manage asbestos safely wherever it is present. It may not be an issue – if it remains undisturbed and it is highly unlikely that there is a significant risk – but turning a blind eye is no longer an option.

CLASAG CELEBRATES 1ST YEAR

The Cumbria & Lancashire Asbestos Support Advice Group (CLASAG) celebrated its one year anniversary recently and had a video made explaining all about the group. The group meets at the Barrow & District Disability Centre.

Following the initial launch in January 2019, the group has seen its membership increase, holding monthly meetings with a variety of guest speakers and experts attending, and proactively promoting its offer to patients and carers. The group is part of a number of services that Blackpool based charity, Disability First, offers to the communities of Cumbria and Lancashire.

Alan Reid, CEO, says: "I'm extremely proud of how the group has grown and to be able to offer victims of asbestos-related diseases help and support through CLASAG. For the past ten years, Disability First has been providing a Welfare Benefits home visiting service for patients.

"We are now in the process of establishing a Lancashire base for meetings of CLASAG as the need is just as great in that area, we look forward to continuing our work with Mesothelioma UK and Asbestos Victims Support Groups Forum UK."

APPOINTMENTS

FIRST MESO NURSE APPOINTED IN WEST MIDLANDS

Sophie Philips has been appointed as the West Midlands' first dedicated Mesothelioma Clinical Nurse Specialist (CNS), based at Queen Elizabeth Hospital Birmingham.

Sophie will join Mesothelioma UK's network of 25 dedicated Clinical Nurse Specialists across the UK. Each of the Mesothelioma UK nurses is based within an NHS hospital and dedicated to providing expert, specialist mesothelioma support, information, treatment and care across the region in which they are based.

Sophie has 15 years' experience working with cancer patients in pre-diagnosis, treatment and palliative care at the Queen Elizabeth Hospital Birmingham. During this time, Sophie began attending mesothelioma multi-disciplinary meetings and support groups which increased her interest in helping mesothelioma patients and their families. She will combine her new role as a Mesothelioma Clinical Nurse Specialist with her existing part-time position as a Macmillan Lung Cancer Nurse Specialist.

This new post has been made possible by a private donation, made by John Blunt from Solihull who lost his wife, Janet, to mesothelioma in 2014. Janet was a GP and after her diagnosis in November 2013, Janet and John approached Irwin Mitchell solicitors to investigate the circumstances of Janet's exposure to asbestos. The generous private donation to Mesothelioma UK is based on the settlement of this case and will fund Sophie's role for two full years, split over the first three years of the position.

MAPS Medical Reporting is a leading provider of high-quality medico-legal expert witness evidence in support of legal claims for injury and disease. The company is also supporting Sophie's new post with a grant to Mesothelioma UK which will part-fund her first year.

Commenting on her new role, Sophie added: "I feel that mesothelioma patients often have quite unique questions and need a bit of specialist support and I'm looking forward to providing this in my new role to people in the West Midlands. There are around 60-80 people diagnosed with mesothelioma in the region each year and I'll be supporting them with practical help and advice, including informing them about clinical trials for which they may be eligible."

NEW RESEARCH MANAGER FOR MESO UK

Mesothelioma UK has appointed Dr Lynn Furber as its new Research Manager. Lynn's main areas of focus will be helping the charity to develop and implement our research strategy, and setting up a new UK research centre.

Lynn's role will also include putting processes in place for us to comprehensively review existing funded research projects, and to allocate funding to others for research and audit work. Lynn will also work on producing and launching our research strategy brochure.

Prior to joining Meso UK, Lynn worked as an NHS cancer nurse for 25 years and was an Associate Professor in a University, before establishing her not for profit company called Healthcare Communication Matters.

We welcome Lynn to the team and look forward to seeing our research strategy implemented to support more research into mesothelioma and enhancing patient care and experience.

FUNDING FOR NEW NURSES

We're delighted to announce that we have secured posts for two new mesothelioma Clinical Nurse Specialists. The posts will be based in the East of England Cancer Alliance at the Mid and South Essex Hospital, and in the Kent and Medway Cancer Alliance at the East Kent University Hospitals.

We're grateful to HASAG (asbestos disease support group) for funding the East of England post and to the Mavis Nye Foundation for funding the Kent and Medway post.

We will be looking to recruit to the posts as soon as possible.

ARMED FORCES

Ministry of Defence (MOD) management of asbestos

The MOD published a report in November 2019 detailing its management of asbestos in defence equipment platforms, buildings, and infrastructure. Some of the key points are summarised here:

The health and safety of our personnel is of utmost importance and we are committed to providing a safe working environment including the continued replacement and elimination of asbestos items wherever practicable.

The MOD has been engaged in work to review the management of Asbestos Containing Materials (ACMs) in defence equipment.

Progressive legislation has restricted and prohibited the use of asbestos in new equipment, but the continued use of existing products and equipment containing asbestos was not prohibited provided the risks of exposure were properly managed.

Following legislation in 1999 on the use of white (chrysotile) asbestos, the MOD has taken steps to reduce and eliminate where practicable the use of ACM in defence equipment. In line with guidance from the Health & Safety Executive (HSE), the safest option is usually to leave asbestos in situ and undisturbed as long as it is possible to do so. The replacement of ACM in defence equipment has therefore mainly been undertaken as and when specific components have required replacement.

The MOD remains committed to reducing the use of ACM across defence equipment, but some ACM components need to remain in use on specific platforms to maintain operational capability.

The majority of asbestos materials in defence equipment are bonded with other materials and embedded within equipment and systems that would not routinely be disturbed outside of a maintenance facility.

The presence of ACMs should, however, be correctly recorded and managed, ensuring that operators and maintainers of equipment are aware of potential risks to health, and that suitable handling precautions are taken during activities where ACM items may be accessed or disturbed.

Through the work that has been undertaken to review the management of ACM it has become clear that these items have not always been correctly recorded and managed across a range of defence equipment. This presents a potential risk to some people of unintended exposure to asbestos fibres.

It is not possible to determine the exact risk to individuals but because most people will not have been in direct proximity to asbestos, it is highly unlikely they will have been exposed at all.

Work continues to identify and record ACM and ensure that the relevant technical and safety information is made available to people as soon as possible.

Defence has a duty to manage and protect people from the risk of asbestos and conforms to the requirements of the UK's Control of Asbestos Regulations 2012 and associated HSE Approved Code of Practice (ACOP). Where asbestos is known it is recorded on asbestos registers and labelled accordingly where required.

However, despite numerous surveys of the estate, previously unknown asbestos containing materials may still be encountered or asbestos may have degraded which could potentially present a risk of unintended exposure.

There may also still be unidentified asbestos in some infrastructure assets and where this is the case there is a presumption that it is present so it can be managed accordingly.

The full report can be read at www.gov.uk/government/publications/asbestos-in-defence-equipment-platforms-buildings-and-infrastructure

'SUPPORTING OUR ARMED FORCES' AT HMS EXCELLENT HEALTH FAIR

On 30 January 2020, Mesothlioma UK Clinical Nurse Specialists, Anne Moylan and Helen Wilkes attended the Health Fair at HMS Excellent in Portsmouth. The event focused on promoting health and wellbeing amongst service and civilian personnel at the base.

There were many stands representing all aspects of health and wellbeing from physical and mental health, health food and alternative therapy stands, and also representatives from organisations such as the British Legion.

Anne and Helen were able to highlight the aims of the Mesothelioma UK – 'Supporting our Armed Forces' project and talk to many members of staff about the issues of asbestos in a military setting. The event was opened by the Rear Admiral Bath who highlighted the importance of maintaining health and wellbeing and awareness of factors that can negatively impact this.

The event allowed Helen and Anne to talk to Rear Admiral Bath, who recognised the importance of the work that Mesothelioma UK were doing in raising awareness amongst the Armed Forces.

JOHNNY MERCER MP INTRODUCED TO ARMED FORCES PROJECT

Johnny Mercer, MP for Plymouth Moor View, met with nurses from Mesothelioma UK on Friday 7 February 2020 at Derriford Hospital in Plymouth to find out more about a major project aimed at raising awareness of, and providing treatment for mesothelioma in the armed forces community.

Johnny Mercer MP served in the British Army for 10 years prior to becoming an MP and in 2019, was made a Parliamentary Under Secretary of State in both the Ministry of Defence (MOD) and the Cabinet Office where he jointly oversees a new Office of Veterans' Affairs.

Johnny Mercer MP met with Christine Jones, Mesothelioma UK Clinical Nurse Specialist (CNS) and Anne Moylan, Mesothelioma UK Lead Nurse for the Armed Forces project, to find out about the impact of mesothelioma in the Plymouth area and to learn more about what the charity's Supporting Our Armed Forces project is doing to support veterans and military personnel with the disease.

Johnny Mercer MP, commented: "It was great to see Chris and the team today; we are working on a flexible compensation package that suits the personal circumstances of veterans with mesothelioma caused by their military service and I look forward to seeing them again in London in due course."

Anne Moylan added: "Mesothelioma UK is delighted to meet with Johnny Mercer MP to raise awareness of our Supporting Our Armed Forces project. It is hugely important, particularly in the areas of Plymouth, Portsmouth and Southampton, given the high incidence of mesothelioma and exposure to asbestos that we've seen from patients in the local area, with people employed at the dockyards or based here during navy service.

"We hope that meeting Johnny will help to raise the profile of mesothelioma, the dangers of asbestos exposure and the availability of support for those in the Armed Forces and wider communities affected by it."

SIGN UP TO RECEIVE NEWS FROM 'MESOTHELIOMA UK – SUPPORTING OUR ARMED FORCES' PROJECT

'Mesothelioma UK – Supporting our Armed Forces' launched an email update back in 2019 aimed at keeping people up-to-date about the project and how we are helping the Armed Forces community and patients with mesothelioma.

Each quarter, we send out an email update. Please go to www.eepurl.com/dNoyfc to sign up or visit the Armed Forces pages on our website at www.mesothelioma.uk.com/armedforces

CLINICAL TRIALS

INFINITE trial for pleural mesothelioma now open

There are limited treatments currently available if Malignant Pleural Mesothelioma (MPM) does not respond to initial treatment. Trizell Limited has therefore developed an innovative investigational gene therapy: a replication-deficient vector (adenovirus) to deliver human interferon (IFN) α-2b gene directly into the intrapleural space. This helps the body produce more of a protein called interferon - specifically in the lining of the lungs. The increased amount of this protein can have effects on the immune system to potentially decrease tumour growth.

Trizell Limited has launched a global phase III clinical trial called INFINITE to determine the safety and effectiveness of this investigational gene therapy (rAd-IFN), when given with the anti-inflammatory Celecoxib, and followed by the chemotherapy Gemcitabine, on slowing or stopping tumour growth.

The trial is recruiting patients seeking a second or third line treatment (one of the previous treatments must have been an anti-folate and platinum combination regimen).

Up to 300 patients will be recruited globally. The UK sites participating in this clinical trial are: Glasgow, Manchester, Oxford, London and Plymouth.

If you are interested in the INFINITE study, would like more information, or want to find a recruiting study location, please visit www.uk.myinfinitestudy.com or www.clinicaltrials.gov (NCT NCT03710876)

Update on clinical trials

- **CONFIRM** is the first-ever placebo-controlled, randomised phase III trial of a PD-1 immune-checkpoint inhibitor in mesothelioma (relapsed and non-relapsed) - closed to recruitment a year ahead of schedule
- **VIM** - a randomised controlled phase II trial of oral vinorelbine as second line therapy for patients with malignant pleural mesothelioma - is now closed, with results due to be presented in 2020
- **MiST** is a multi-arm stratified therapy based clinical trial for patients with relapsed mesothelioma:
  - MiST1 results to be presented in 2020
  - MiST2 is now closed
  - MiST3 is due to open Q1 2020
  - MiST4 is open and recruiting
  - Further MiST arms are in development
- DENdritic Cell Immunotherapy for Mesothelioma (**DENIM**) is now open and recruiting. Patients who have had evidence of disease control during chemotherapy may be eligible

MARS 2 IS STILL SEEKING PARTICIPANTS

MARS 2 (Mesothelioma and Radical Surgery 2) is the first ever trial to compare the effect of treatment with chemotherapy and a lung-sparing operation called 'extended pleurectomy decortication', or treatment with chemotherapy only (standard care) on the quality and length of life of patients diagnosed with mesothelioma.

The lung-sparing operation used in MARS 2 is currently offered by the NHS, but it is not known whether it offers the most effective treatment option for patients with mesothelioma. MARS 2 has been designed to provide evidence to address this important issue so that the best treatment option can be offered to mesothelioma patients. This important study, funded by the NIHR and led by Professor Eric Lim at the Royal Brompton Hospital, is continuing to recruit until 1 June 2020.

MARS 2 is taking place in 26 hospitals throughout the UK, from Glasgow to Plymouth.

Currently, 296 patients have been recruited to the MARS 2 study. We need a further 32 patients to reach our target of 328 by the start of June.

For more information about MARS 2, and to find the locations of the hospitals taking part please visit www.cancerresearchuk.org and search for 'MARS2', email: ubh-tr.mars2@nhs.net stating where you live so that we can direct you to your closest MARS 2 hospital, or speak to your oncologist or doctor at your local hospital. As a thank you for taking part in the study your travel expenses will be covered for any research visits outside standard care.

FUNDRAISING

CHEQUE PRESENTED BY MAYOR OF SAFFRON WALDON

Mayor of Saffron Walden, Councillor Arthur Coote's latest fundraiser has raised £3,000 for Mesothelioma UK. The 1960s dance and disco was held at Saffron Walden Town Hall on Saturday 19 October 2019.

Mesothelioma UK clinical nurse specialist, Kate Slaven, was presented with the cheque on 12 December at Royal Papworth Hospital NHS Foundation Trust.

The Mayor had become aware of the charity after his close friend was diagnosed with this asbestos-related cancer. His friend is being cared for as an outpatient at Royal Papworth Hospital and at Addenbrookes Hospital in Cambridge.

Councillor Arthur Coote, Mayor of Saffron Walden commented: "Having a life-long friend, born and bred in our town, who has suffered from this disease I decided, as Mayor of Saffron Walden, to try to raise money for research into the cause of this disease. The people of Saffron Walden supported this wholeheartedly and our 60s Reunion Dance managed to raise £3,000 which will be spent on research."

Head of Services for Mesothelioma UK, Liz Darlison added: "We're so grateful to the Mayor of Saffron Walden for this generous donation and his support in raising awareness of mesothelioma. Our aim is to ensure equitable access to world-class treatment and care and to raise awareness of mesothelioma so this and every other donation we receive is so important in helping us to achieve these aims."

SHEILA'S THREE CASTLES CHALLENGE

"My husband Ken was diagnosed with mesothelioma in May 2017. Since his diagnosis, he has undergone chemotherapy and has been on the CONFIRM immunotherapy clinical trial. He remains positive every day and fights to stay as active as possible while he can. He is an inspiration to many and that is why I decided to complete the Three Castles Challenge for Mesothelioma UK.

"I completed the Snowdonia Half Marathon in May last year, the Bangor Half Marathon in October and finally the Conwy Half Marathon in November."

Sheila raised an incredible £930 plus £138.75 Gift Aid, making her total £1068.75!

FUN AND FUNDRAISING AT KAREN'S BIG BIRTHDAY BASH

Karen's partner, Bob Newing, was diagnosed with Epithelioid Mesothelioma in February 2019, and since the diagnosis, the Meso clinical team at Guy's hospital has provided care and support to both of them. Bob underwent surgery to remove fluid from his lung, followed by chemotherapy and thankfully his condition is currently stable.

Karen and Bob have a real zest for life, and they haven't let Bob's diagnosis stop them from enjoying life by getting out and about and even going on long haul holidays. Karen and Bob wanted to recognise the excellent work of the Meso clinical and research teams and HASAG, in the pursuit to find a cure for this aggressive cancer.

On Sunday 20 October 2019, Bob and Karen threw a big party at a local restaurant in Eastbourne to celebrate Karen's 60th birthday. In lieu of presents, Karen asked friends and family to donate to Mesothelioma UK. Everyone was so generous and they raised £1,101.25 for Meso UK. Karen and Bob say: "It was a fantastic day we will never forget". Bob will be 70 in March 2020 and so they are now planning their next fundraising celebration!

PHIL MORETON FUNDRAISING

Kirsty and her five children have been tirelessly fundraising for Mesothelioma UK since October 2019 when they lost their husband and father, Phil Moreton to the disease.

When Phil was young, he had fallen through a garage roof that contained asbestos and also lived in a house lined with asbestos.

Kirsty and her children have worked incredibly hard by making gifts and jewellery, and selling it at local events in Gosport as well as collecting money on the High Street in November. The Mayor of Gosport is among the many people who have donated.

Kirsty has also been making an impact in the news with a number of televised interviews, further supporting the charity by raising awareness. Since October, Kirsty and her family has already raised a fantastic £435 and they will continue to support Mesothelioma UK.

EMMA'S CHARITY EVENT RAISES £5953 FOR MESO UK!

"I am pleased to say our recent charity event for Mesothelioma UK was a huge success.

"We had an amazing Robbie Williams tribute called Dan Budd as well as a raffle and auction.

"The event was held at The Mercure Hotel in Bewdley in memory of our loving father, husband and grandfather, Michael Reedman, who passed away seven years ago with mesothelioma. We are so pleased we have raised money to help support others affected by this awful disease."

MELVYN ROBERTS

"My Dad, Melvyn Roberts, was my hero. I know everyone thinks that about their Dad but it's true! He was kind, selfless and his sense of humour was one of a kind, even during his darkest days - he saw the funny side of everything.

He adored my Mum and they had a fairytale love story - met at 15, married at 18 and had five wonderful children. Last year would have been their 55th anniversary.

The irony is, my Dad signed his death warrant before me and most of my siblings were born. In 2018 our nightmare began after he went into hospital to have his lungs drained and he was diagnosed with mesothelioma.

He had six rounds of chemo, ending in early 2019, after that he deteriorated quickly and his mobility was limited. Me and my sister would take him the cinema, he loved films but he didn't feel able to go anymore, and we haven't been able to go back to that cinema since.

Things got worse when he was admitted to A&E in March, and he stayed there until he died peacefully later that month - a day we can't forget. The funeral was held on April Fool's Day, because we know he would have loved that!

There is nothing like the loss of a parent, time makes no difference. I have no idea how my Mum has managed to carry on, always putting us first, she has such strength.

This year my colleagues suggested we raise funds for Mesothelioma UK and we have all been trying to raise as much as possible.

I love talking about my Dad. It keeps his memory alive and he deserves that because he gave everything of himself to his family, asking nothing in return."

Kelly raised £600 for Mesothelioma UK and plans to take on a 12 hour spin-a-thon in March!

GORDON FEE'S 80TH BIRTHDAY BASH

Gordon was diagnosed with mesothelioma in September 2018. Whilst undergoing treatment on the Mesothelioma MARS 2 trial, he was very grateful for all the help and advice mesothelioma specialist nurses had given him, and also to his local 'Messy' mesothelioma support group, who have helped him to remain positive throughout his recovery.

To mark his 80 birthday, Gordon organised a pizza and quiz night at his local church. Most of his guests had no idea what mesothelioma was and very few could pronounce the word. Gordon obtained a DVD from Mesothelioma UK which was very informative and he showed part of it as an introduction to his celebration.

It was a fabulous evening, raising £800.00.

BE BEAUTIFUL IN MEMORY OF PATRICK O'BRIEN

Emma O'Brien held a charity event at her beauty salon by turning it into a cocktail bar for the evening and raised £593.00.

MARILYN LERNER QUIZ NIGHT

"On Thursday 5 December 2019 I hosted a theatre quiz night to raise money for Mesothelioma UK. The quiz was in memory of my precious Mum - Marilyn Lerner who lost her battle in April 2019. A hole has been left that can never be filled, though her love and legacy lives on in my heart.

"The event was held at Fego in St John's Wood, NW8, London, who generously donated to the cause. The cafe was apt as my Mum went there seven days per week, and the manageress Daniela has even put up a plaque where Mum used to sit. The quiz was amazing and everyone had a great time as well as raising over £5,000 for Mesothelioma UK!"

MICHELLE REMEMBERS DAD ON WEDDING DAY

"Dad was diagnosed with mesothelioma in October 2017 and not long after diagnosis, I began to plan my wedding to Daniel. We booked the date of 4 May 2019 and hoped that Dad would be able to give me away.

Dad was young and relatively fit and healthy, apart from his mesothelioma. As a result, his oncologist suggested he looked at clinical trials and in particular the MARS 2 trial.

We discussed the trial as a family and he agreed to take part. Unfortunately, Dad was not selected to have surgery and he continued with his chemotherapy treatment.

After this, his oncologist suggested we look at other trials and Dad signed up to take part in the VIM trial. Unfortunately, before the trial treatment could start, Dad contracted a chest infection and sadly passed away on 14 June 2018, aged 63.

In July, I ran the Race for Life Pretty Muddy with my two best friends. I was worried it would be a really emotional day and it was, but also was such an inspiring and positive day at the same time. We raised over £1,000 which we were so pleased with as we had initially hoped to raise £200.

Our wedding was fast approaching and I wanted to somehow include Dad in our special day. I agreed with my fiancé that we would not have wedding favours for our guests but instead donate in Dad's name to Mesothelioma UK.

We also asked guests not to buy us gifts and instead requested that they make a donation in Dad's name. We were overwhelmed to learn that in total we had raised over £1,330 in memory of Dad.

Daniel was also really close to Dad and we both somehow wanted to include him in the wedding day, and therefore we made a memory ladder, full of flowers, candles and photos of Dad and us all as a family. They were all quite fun photos that our guests could look at and they made us laugh, smile and fondly remember Dad.

When Dad was ill the clinical trials that Mesothelioma UK support gave us all such hope as a family that one day a cure and improved treatment would be found.

I would encourage anyone to fundraise for Mesothelioma UK – it helps you feel like you are doing something so worthwhile and positive to help your loved ones."

SWING FOR MESO

David Nurse is a mesothelioma patient who is determined to raise funds and awareness. As a keen golfer, David has organised a charity golf day and hopes to establish a support group for patients who, despite their condition, still like to enjoy golf. David shared this with us:

My name is David Nurse and unfortunately, I was diagnosed with mesothelioma in November 2018.

When I was first diagnosed with mesothelioma I was told there was no cure for the condition and that my life expectancy was 4 to 7 months, but because I was in general good health and fit for my age I may even make 12 months.

I underwent surgery on 13 December 2018. Whilst being prepared for the surgery I'm told all I could talk about was when would I be able to start playing golf again. This target kept me going through January and February, and with the aid of a sit-on buggy to help with my breathlessness, I was playing again by April 2019. By June I was playing well enough to be picked to represent my club in the senior team matches.

I want more than anything to show my appreciation to Mesothelioma UK and the healthcare professionals who have supported me by organising a golf competition to raise money to help them continue the excellent work they are doing and to improve local services.

I have sponsorship from Slater and Gordon solicitors and have also been able to secure the use of Blackley Golf Club in Manchester on Friday 17 April 2020 for a Charity Golf day.

I would also like to establish a support group for fellow golfers and mesothelioma patients.

If you would like to get involved in the charity golf day or have an interest in a support group, please email swingformeso@yahoo.com or call David on 07952178416.

CREATE A LEGACY BY LEAVING A GIFT TO MESO UK IN YOUR WILL

Making a will can be easy and is there to make sure that your wishes are carried out after you've gone, giving peace of mind to you and your family. And that's why Mesothelioma UK is working with a firm of solicitors to offer a free will-writing service.

For Meso UK, receiving a gift in a will is an honour; it reminds us of the commitment and generosity of our supporters and helps us to plan for the future.

Even when you or a loved one are no longer here, it is never too late to support Meso UK in our work to help others. You can arrange to leave a gift in your will, as a lasting legacy that will truly benefit others who have been affected by mesothelioma.

Legacy gifts can have a huge impact on charities like us, which rely on donations and sponsorship.

If you would like to know more about the free will-writing service and/or how to leave a legacy in your will, visit www.mesothelioma.uk.com/getting-involved/donate/, email info@mesothelioma.uk.com or call 0800 169 2409.

THE JIM FRIAR ANNUAL MEMORIAL QUIZ

On 29 November 2019, around 100 family and friends gathered for the 4th annual 'Jim Friar Memorial Quiz'.

Jim was a much-loved husband to Teresa and father to James and Joe, and his delight in a round of golf made it fitting that the event be, once again, hosted by Jim's old club, Bewdley Pines Golf Club.

A quiz is an appropriate way to remember Jim as he was a great quizzer and regularly set quizzes for local charities.

Jim sadly passed away in May 2016 only 12 weeks after receiving his diagnosis of mesothelioma.

Jim had a huge number of friends in the local community and they turned out in force to remember him. The quiz was a great success with brain aching questions, a ploughman's supper and a raffle followed by an auction of gift baskets donated by friends and local businesses. The trophy, presented by Teresa, was carried away by the winning team to much cheering and applause from the other teams.

The total raised was a whopping £1,570, of which £1,320 will be donated to Mesothelioma UK and £250 to West Midland Asbestos.

Teresa said: "I would like to thank everyone who turned out on a cold night to remember Jim and honour his memory with fun and laughter."

MURRAY BROWN

"My husband, Murray Brown passed away from mesothelioma after a diagnosis in 2015 - he was only 52. He had a 12-month length of time to live but survived to 31 August 2019. In that time, we did so much by way of weekends away and holidays. Murray strove to work from home and was involved in many engineering design projects. He will be much missed by family and friends.

"Above all, he was a true Christian and his faith throughout his illness kept him calm, uncomplaining and above all, gave him the perseverance to endure all that he had to."

Linda donated £305 from donations received at Murray's funeral.

D'ARCY MANNERS SPONSORED DISNEY COASTER RIDES

"My Grandpa died suddenly and without warning in April 2017; I never got the chance to say goodbye. My Grandpa was my best friend in the whole world. He would pick me up from school every Thursday and we would have fun making Lego models, colouring and watching SpongeBob SquarePants.

"Even though he's been gone for more than two years, I still miss him every single day. I talk about him all the time and wish he was still here with Nanna and their dog, Tallulah.

"My Grandpa was great at drawing, was very clever and I used to love watching 'Strictly Come Dancing' with him."

In the summer of 2019, D'arcy rode the top five Disney roller coasters in Florida and raised an incredible £537.24 including Gift Aid, in memory of her Grandpa, Derek Manners.

CHALLENGES AND A CHARITY NIGHT FOR MIKE

Family and friends have rallied around mesothelioma patient, Mike, who was diagnosed in June last year and sadly passed away three months later, to raise funds for Mesothelioma UK. On 2 August, Mike's son in law, Daniel Forster and three of his friends, Chris Tomlinson, Paul Reay and Jason Chapman took on the Welsh 3000s Challenge, which requires hikers to reach the top of all 15 of the mountains over 3000 ft and covering 30 miles, within the space of 24 hours, without using any form of transport.

The challenge unfortunately got the better of them due to logistical problems at the start which set them back, and poor weather conditions saw them arrive just short of Snowdon's summit by the end of the first day. They woke the next morning with fresh motivation, until an injury set them back by a further three hours. Battling injuries and weather conditions, the team pushed forward and conquered the monster summit of Elidir Fawr. Despite not completing the challenge due to safety concerns, they covered 23 miles and found the experience challenging but extremely rewarding. The team raised £1,245 for Mesothelioma UK.

Daniel says "I'd like to say thank you to everyone who has been so kind and generous and donated to such an amazing charity. I've witnessed first-hand how they make the lives of people suffering with such a devastating illness that little bit easier."

Mike's daughter, Natalie Bartley, also hosted a charity night at Rainhill Ex-Services Club in Liverpool on 17th August. Natalie sang for the band Identify X which formed in a matter of weeks on the lead up to the event and blew everyone away with their talent. Her 8-year-old son helped all evening and made his grandad very proud indeed. Glitter tattoos were also available for the attendees, and everyone thoroughly enjoyed the bingo and raffle. Natalie said she wanted to thank everyone "a million times over" who donated prizes and to the club who provided their venue free of charge and provided decorations.

The total amount raised was split between three charities that have supported Mike and his family. Mesothelioma UK received a further £400 from the family.

MANCHESTER HALF MARATHON FOR MESO

In October 2019, Louisa Saville from Leigh Day solicitors Manchester, completed the Manchester Half marathon in aid of Mesothelioma UK. Louisa says: "It was a bit of a soggy day, but I got around in 2 hours 10 minutes which I was really pleased with. I was even happier to have raised £880 for Meso UK!"

Louisa managed to raise an amazing £1,019.31 including Gift Aid!

GEORGE GENERATES FUNDS AT FAMILY WEDDING

Nine-year-old George recently collected funds at his great uncle's wedding to support his grandad who has mesothelioma. He had a strict policy of 'notes only'! With this attitude we are sure George will continue to make his grandad very proud.

Mesothelioma UK exists to raise funds to support the services that we provide and any sponsorship, grants or donations made to the charity support this.

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

If you would like to find out more about becoming a corporate donor, please contact us on 0800 169 2409 or email info@mesothelioma.uk.com

Events Calendar

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

Peritoneal Mesothelioma Event
24 April 2020
Apollo Hotel, Basingstoke
www.mesothelioma.uk.com/events

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

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

Action Mesothelioma Day
3 July 2020
www.mesothelioma.uk.com/events

'Meso on the Med' Awards Night 2020
1 October 2020
The Harbour Hotel, Southampton
www.mesothelioma.uk.com/awardsnight

Patient and Carer Day
2 October 2020
The Harbour Hotel, Southampton
www.mesothelioma.uk.com/pcday

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

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