Mighty HASAG

Asbestos support group HASAG (Hampshire Asbestos Support and Awareness Group) continues to support our crucial mesothelioma research work, and it is amazing how much money is raised every year. A recent donation of £20,000 from AMD 2015 follows last December’s £15,000 cheque from the proceeds of AMD 2014.

Lyne Squibb and her sister Lisa – whose father Dave Salisbury sadly lost his life to mesothelioma in 2005 – organised a range of fundraising activities, including a raffle and a dove release, with over 150 patients and their families attending.

Lyne said: “We hope this will go a small way to help with further research.”

Mesothelioma nurse Anne Moylan and Penny Mordaunt MP for Portsmouth North were among speakers at HASAG’s AMD day, and led honours in releasing white doves in a symbolic gesture of remembrance. Just over 160 people attended from all over the south of England.

Lyne Squibb said: “We are so lucky to have had such amazing support from our patients and their families.” HASAG have raised and donated more than £200,000 for research into mesothelioma in the last six years; they are truly the UK’s top meso campaigners.

We are overwhelmed and grateful for the continuing support of HASAG. Not only do they do wonderful work for mesothelioma sufferers and their families, but they are fantastic fundraisers. Thank you so much once again to Lyne, Lisa and Ali, and everyone who supports HASAG.

Bastow’s mammoth cycling fundraiser

London Company Bastow’s, contacted the JHMRF with a desire to raise money for mesothelioma research. The company’s CEO, Frank Bastow, lost his father to mesothelioma in 2012 and felt strongly that as a construction company he kept hearing many horror stories around asbestos. He said he has seen “too many lives lost to an illness that can and should be prevented by good education, responsible management and proper care for workers.”

A wonderful team of people challenged themselves to the Newcastle to London cycle race on 22nd and 23rd August this year, including contracts director Nimesh Bharadia, the company’s health and safety chief. The initial target was £2,000 to pay for another year’s mesothelioma patient support group meetings in Leeds.

After a gruelling 305 miles and 26 hours the total amount raised was more than twice that - £4720.

Cultural Director Niki Rosenbaum said: “I am so proud of our guys and delighted that they did this for such a great cause.”

Well done and a huge thank you to Bastow’s and everyone who contributed to the wonderfully generous donation for mesothelioma research.
About the Fund and June

Family and friends wishing to carry on June’s quest for justice, and to help other sufferers both now and in the future established the June Hancock Mesothelioma Research Fund in 1997 shortly after June’s death from mesothelioma.

June’s mother, Maie Gelder, also died from mesothelioma in 1982 and it was that double tragedy that led June to seek justice in a test case against the owners of the J W Roberts asbestos factory in Armley, Leeds. They had negligently contaminated their own workforce and the local neighbourhood with deadly asbestos dust. This was described as a true “David and Goliath” battle and against all the odds June won her case and proved that T&N were negligent.

June was 61 years old and her Mum 67 years old when they lost their lives to mesothelioma – exposed as a young innocent family living in the shadow of the factory.

The founders of the June Hancock Fund pledged to continue raising awareness of the disease, helping provide up to date quality information and advice, and to finance independently reviewed specific mesothelioma research projects.

We continue June’s battle in her name. For contact details see back page.

For a full list of our trustees and founders please visit our website

www.junehancockfund.org

FUNDRAISING

Copping Brothers’ tribute to their Dad

Brothers Tom and Richard Copping lost their father Brian to mesothelioma in 2012. They decided to raise money for research into the disease that took their father by taking on the U.T.L.D Lakeland 50, a gruelling ultra marathon in the Lake District on July 25th this year. Finishing the race in 292nd position out of 610, and after 14 tough hours they raised £2,620, well over their target.

Fund chair Kimberley Stubbs said: “This was a wonderful achievement and a big thank you from us to Tom and Richard and to everyone who helped and contributed.”

Tom said: “Dad enjoyed walking in the hills, especially the Lake District, Peak District and Yorkshire Moors, and was planning to complete the 40 mile Lyke Wake Walk across the North Yorkshire Moors from Osmotherley to Ravenscar. We wanted to complete something gruelling and challenging in his name – it doesn’t get much tougher than a 50-mile mountain ultra marathon on rough terrain with an approximate 3100m ascent.

“The final climb and descent was to the finish at Coniston. The brothers described it as ‘a truly amazing route.’

Dancing for a cause

Julie Dixon organised a charity Zumbathon at the North Walsham Community Centre, with ‘Zumba Jools’ describing it as ‘fun disguised as exercise’ to raise a target of £100 to help fund mesothelioma research in memory of Thomas Henry Withers. A loving husband and father, Thomas died as a result of the disease in 2002.

Thanks to Zumba Jools and everyone who took part, a staggering £825 was raised for mesothelioma research.
Action Mesothelioma Day

The JHMRF and MesSY work in partnership throughout the year and co-produce an annual Action Mesothelioma Day event.

MesSY is a local patient group led by Specialist Nurse Simon Bolton. Mesothelioma Support Yorkshire (MesSY) meets every six weeks in Leeds city centre and draws patients and carers from a wide radius across the Yorkshire region.

The AMD 2015 event was held on Friday 3 July at Weetwood Hall, Leeds. This year we returned to our popular ‘Meet the Experts’ format – a form of speed-dating for researchers where patients and carers are able to sit down face to face with experts from a range of different backgrounds for a series of informal question and answer sessions about mesothelioma research and treatment. Lots of interesting topics were covered from cell biology to the role of the specialist nurse, and organic chemistry to surgery. It was wonderful to see so many people attending what was both a day of fellowship and a day of information gathering and sharing. Speaking afterwards, Kimberley Stubbs daughter of June Hancock and Chair of the Fund said “bringing people together through their experience of mesothelioma helps so many, just knowing that you are not alone. And having an opportunity to “meet the researcher” is really welcomed by mesothelioma sufferers and their families. It was a lovely sunny day, a lovely afternoon tea and a day that everyone seemed to enjoy”.

Action Mesothelioma Day 2016 will take place on Friday 1 July. More details of the Leeds event including how to book your place will be available in the New Year.

For more information on this or on any of our work please visit our website www.junehancockfund.org or email the Chair directly info@junehancockfund.org

We Are Making a Difference
Thank you to all who make it possible.
Some newsletter readers may have met Adrian at one of our AMD events in Leeds.
A lovely, personable man and hugely dedicated to mesothelioma research, here is what he wrote for us, and for you.

I should begin with a confession. I am a chemist. I studied chemistry. Worse than that, I like chemistry! That is usually a conversation killer, so congratulations if you are still with me. I like mixing things together and seeing what happens – perhaps I missed my true calling to be on the Great British Bake Off! And fortunately, they don’t (often) go bang, as in school chemistry.

I graduated in 1992, and enjoyed the subject so much that I studied for a PhD in organic chemistry, graduating in 1996. I was then very excited to take up a research position at the Université catholique de Louvain, in Louvain la Neuve, just outside Brussels in Belgium. Belgium is a fantastic country, and I cannot recommend it highly enough. I thoroughly enjoyed living there for two years. Everything in my life was great at this point; I had never heard of asbestos.

After I had been living in Belgium for a couple of months, my parents came out to visit me for the first time, driving over via the relatively newly opened ‘Le Shuttle’ through the ‘Chunnel’. I thought that they looked tired, but put this down to them both being retired and a long drive. However, during their 5 day stay, my dad never quite got back to his usual self, and a short while after returning home to London, decided to see his GP, who referred him for a few tests. Nevertheless, provisional plans were in place for future visits to Belgium in 1996.

These never happened. It turned out that the reason for my Dad’s tiredness/breathlessness was fluid in his lungs, which they removed by means of a drain. This happened many times. Then they started asking the question – casually at first – had he ever worked with asbestos? ‘No’ came the reply from my father. But when he was working, he had been a charted civil engineer, working on many projects including the Hallamshire Hospital in Sheffield. As he thought about things, he remembered that – while still an apprentice – he had been on site visits to the GPO tunnels under the Holburn region of central London, and the workforce had been spray-lagging the tunnels with a mixture of cement and asbestos – despite the thick clouds in the tunnels, none of the men wore any face/noise protection.

Then came the phone call from my parents – long distance of course as I was still in Belgium. “Your dad has been diagnosed with mesothelioma.” “With mee-zo… what?” At the time none of us knew what this meant or the implications. While we cannot ever fault or complain about the care he received through the NHS and later South Bromley Hospice Care and St Christopher’s Hospice, the one thing no one ever said was the implications on life expectancy or that it was a terminal disease. I believe the only comment he received was that it would ‘affect his life expectancy’ but little more than that. Being relatively ‘geeky’, I was really interested in this new ‘thing’ that was really taking off in 1996-7 called the ‘internet’ and used it to find out what I could for my Mum – and always with the purpose of addressing mesothelioma research – we didn’t tell my Dad everything we learnt, but information was generally scarce. The one excellent piece of information we had was a small booklet by Mavis Robinson, a MacMillan nurse, I believe associated with JHMRF. I am an only child, and in due course, I was able to leave my position in Belgium and return to the UK and to live at home with my parents during my Dad’s last few months, before he passed away in July 1998.

I have always loved university life, and have never truly left university – even some 26 years after originally going up to King’s College London in 1989. Over the years, I have developed my own independent research group, working in the field of organic chemistry – that is making molecules – and always with the purpose of addressing medicinal problems. However, one nagging doubt always remained at the back of my mind – why had I never got involved in any mesothelioma research?

The answer was simple – where do you start? Let me give you some background to medicinal chemistry. Nearly all drugs on the market, for any condition, have somewhere in their history, as a starting point a compound from nature. This often comes from folklore. For example, aspirin originated from a compound found in the bark of the willow tree; many modern painkillers are derivatives of extracts from poppies, including morphine. Ephedrine, first isolated in 1923 from a plant long used in traditional Chinese medicine was the foundation for the development of the anti-asthma agents salbutamol and salmeterol. Rhubarb extracts have led to some modern laxatives. And so the list goes on.

Chemists need a starting point for their work, and for mesothelioma, there was no such starting point.
A personal and professional perspective by JHMRF research award recipient and organic chemist Professor Adrian Dobbs

All that changed in 2009, with the report of a compound, termed JBIR-23, by a group of natural products chemists in Japan. They claimed that this natural product showed some (albeit not great) ability to kill mesothelioma cancer cells. What a breakthrough – our starting point! We attempted to start work looking at this molecule straight away, our chemistry-heads racing with possibilities about how this compound may work and how we could try and develop it.

However, drug discovery is an expensive business! We were very fortunate that the JHMRF saw the possibility in this compound, and we entered into an agreement with them, and one of their major benefactors, the sadly deceased Steve Lee, to fund initial research into this compound. We initiated a collaboration with Dr Peter Szlosarek at Bart’s Cancer Institute in London, who would test all the compounds that we made against the mesothelioma cancer cells. Our work involved making chemical compounds. We passed these to Bart’s for testing – they tell us if the compounds are any good or not (that is, were they effective at killing the cancer cells). They also test the compounds against healthy human cells, to check there are unlikely to be side effects. We use this information to design more compounds, make them, get them tested, and so the cycle goes on, until hopefully we reach a point where we have a small number of compounds we can progress to studies outside the test tube and into animals in the first instance.

To an extent, this is where luck plays a part in the whole process, in that you hope that you can find those ‘perfect’ compounds as quickly as possible. Unfortunately, we are still in that cycle of manufacturing and testing – mainly limited by limited resource and not enough manpower – universities cannot throw 20 chemists at the problem in the same way that the big pharmaceuticals can. On the other hand, even if it is slow progress, at least we are looking at potential new developments for mesothelioma, which the pharmaceutical firms on the whole are not.

In January 2013, I moved to my current position as Professor of Organic & Medicinal Chemistry at the University of Greenwich, on their Medway campus near the Chatham dockyards – itself a hotbed of asbestos with a terrible legacy of asbestos-induced diseases. Our work has really gathered pace since being at Greenwich, and the University is very supportive of this. Even more exciting, since the discovery of JBIR-23, three more natural products have been isolated which also show good levels of anti-mesothelioma activity. We are now looking at all of these compounds, with the idea to see if there are any common features in their chemical composition or ‘make-up’ which may give clues to their mode of action, and which we would incorporate into more efficient agents, but without harming normal healthy cells in the body. The University of Greenwich has been very supportive of our work in this area, and featured it as part of their Alumni fundraising campaign in Summer 2014, with the aim of raising sufficient funding to cover the costs of the chemicals and other laboratory consumables for a new PhD student starting in our laboratory in October 2014. More generously, the JHMRF agreed to match fund penny-for-penny the money raised by the Alumni campaign, which now stands at several thousand pounds, with money still coming in. Further, the University supported a fundraising initiative on behalf of our mesothelioma research at the first Action Mesothelioma Day in Medway in July 2015. Our local Medway MP Tracey Crouch is visiting our laboratories on 12th December as part of her interest in campaigning for mesothelioma victims in Parliament. For those who use twitter, you can follow our progress at @MesoUoG.

Dr Kate Hill and all from the JHMRF have been fantastic in supporting our work, and recently visited us at Greenwich to meet the new PhD student, Perry Devo and to see our laboratories.

I cannot express how exciting a time it is for us in this research. The drug discovery process is a long and arduous one, with no guarantees ever of success; it is the literal ‘needle in a haystack’ in terms of finding that correct chemical structure that will do what you want it to do, without harming the rest of the body. As I write this, I cannot offer any promises that we will ever make it. What I can do, however, is assure you that every penny we have received from our generous supporters is used to further our knowledge and understanding of mesothelioma.

Thank you for everything you do in mesothelioma research Adrian.
Radiotherapy helped one in three in largest ever trial

A JHMRF-funded fellowship to assess the effectiveness of radiotherapy in treating mesothelioma found that one in three patients benefited from some pain relief, with one in eight recording a complete resolution of their pain.

The results were published in the Journal of Thoracic Oncology in June 2015, and are available to read online here: http://journals.lww.com/jto/Fulltext/2015/06000/ls_Radiotherapy_Useful_for_Treating_Pain_in.12.aspx

14 patients had improvement in their pain five weeks after the radiotherapy, with five having a complete resolution of their pain. No changes in other factors or symptoms such as breathlessness or quality of life were detected, (apart from a small improvement in night sweats) but this could be explained by the relatively small number of participants.

Nicholas Macleod said: “The improvement seen in pain control in this study gives us grounds for optimism. The study would not have been possible without the support of the JHMRF and I cannot thank the charity enough for awarding me the Brother Peter Fellowship which enabled me to carry out this work.”

Several other publications have drawn on this important study; see our website for further links. The follow-on study, the SYSTEMS-2 trial, was funded by the JHMRF in the latest round of competitive research applications. Dr MacLeod said: “I’m delighted to continue the partnership with the June Hancock Fund and to have the opportunity to take this work forward to the next phase.”

If SYSTEMS-2 is successful, there is potential for the findings from this study to be widely implemented in practice and have an immediate impact on patient care.

The JHMRF awarded two PhD fellowships in the 2014-15 funding round. The Stennett Fellow, Dr Suzanne Graef, was appointed in January 2015. She will work under the supervision of Professor Gary Middleton. Her project will deliver the first comprehensive analysis of myeloid-derived suppressor cells in mesothelioma and the effects of therapies aimed at targeting them. This fellowship offers a unique training opportunity in translational cancer immunology.

A PhD fellowship in organic chemistry has been established as a result of the ongoing fund raising partnership between the JHMRF and the University of Greenwich. Perry Devo was appointed in October 2014 to work under the supervision of Professor Adrian Dobbs. He will refine and test a compound that has been shown to prevent proliferation of mesothelioma cells in tissue samples.
The James Lind Alliance

Research into mesothelioma has been highlighted as a priority by the National Institute for Health Research (NIHR). Recognising the need for more research on prevention and earlier diagnosis of mesothelioma, as well as the treatment or care - including palliative care - for patients, the NIHR has initiated a package of measures to boost research activity including the Mesothelioma Priority Setting Partnership.

This project, led by the James Lind Alliance brought together patients, clinicians and patient organisations to investigate the most important research questions for mesothelioma research. Top priorities were submitted to the National Institute for Health Research (NIHR) and a themed call for research proposals followed. The final report is available on our website:

www.junehancockfund.org

Professor Dame Sally C. Davies FRS FMedSci, Chief Medical Officer and Chief Scientific Adviser at the Department of Health, said:

“I would like to thank all the people who have contributed their ideas and suggestions, and the partner organisations who have supported this tried and tested process. With their help I believe we have built a genuine consensus - and a real impetus. I hope the research community will now respond by generating new research proposals that will provide robust evidence to help people with mesothelioma.”

These are the agreed ‘top 10’ most important questions about mesothelioma for researchers to answer:-

1. Does boosting the immune system improve response and survival rates for mesothelioma patients?
2. Can individualised chemotherapy be given to mesothelioma patients based on predictive factors (e.g. the subtype of mesothelioma (epithelioid, sarcomatoid, or mixed), or thymidine synthase inhibitor status (the protein that drugs like pemetrexed act against), etc.)?
3. What is the best way to monitor patients with diffuse pleural thickening and a negative biopsy who are considered to have a high risk of developing mesothelioma (e.g. repeat biopsies, imaging, etc.)?
4. In mesothelioma patients, what is the best second line treatment (i.e. what chemotherapy drugs should be used if a cancer has recurred following first line chemotherapy, usually with cisplatin and pemetrexed)?
5. Which is the most effective current treatment for ascites (excessive accumulation of fluid in the abdominal cavity) (e.g. denver shunt, pleurex catheter, etc.) in patients with peritoneal mesothelioma?
6. What are the relative benefits of immediate standard chemotherapy compared to a watch and wait policy for mesothelioma patients?
7. For mesothelioma patients, what is the best follow-up strategy post-treatment, to identify and treat emerging side effects and other problems?
8. In mesothelioma, is there a role for intrapleural immunostimulants (a drug designed to stimulate an anti-cancer immune response, such as corynebacterium parvum extract) in addition to any other treatment?
9. Does an annual chest x-ray and/or CT scan and medical examination in high-risk occupations (e.g. carpenters, plumbers, electricians, shipyard workers) lead to earlier diagnosis of mesothelioma?
10. What, if any, are the benefits of pleurectomy (pleurectomy/decortication) compared to no surgery, and which mesothelioma patients might benefit?

Travel and educational grants

The JHMRF awards up to 10 travel grants each year. Applications will be considered from researchers and health care professionals to support travel to conferences where applicants will either present papers or speak to a poster exhibit. In certain circumstances, grants may also be awarded for educational purposes, for example, for a study visit to an academic centre of excellence or to attend a course. Applications for co-sponsorship with other organisations or institutions are welcome. Individuals may apply for up to a maximum of £500 in any one year period.

Gene therapy destroys meso cells

Gene therapy is a novel approach to cancer treatment. Simply, it introduces a new gene to re-programme T-cells, the white blood cells of the immune system, so that they target and destroy cancer cells. This new gene is known as a “CAR.”

King’s College scientist Dr Astero Klabatsa received JHMRF funding for a one year study to investigate the use of a harmless virus to deliver two CAR genes into T-cells from the blood of mesothelioma patients. She completed her experiments in August this year. Astero found that the new genes gave the immune cells the ability to attack mesothelioma cells and she also showed that it is feasible to grow the cells in the laboratory to produce a sufficient ‘dose’ of cells that could be used to treat an adult patient.

This study paves the way for clinical testing in patients with mesothelioma in the near future.

www.juneh Hancockfund.org
Oncologist researcher conference debut

Dr Fiona Taylor attended the 13th British Thoracic Oncology Group Conference in Dublin in 2015 supported by the JHMRF. Dr Taylor is training to be an oncologist at the University of Sheffield. The three-day conference brought together a range of people involved in mesothelioma or lung cancer research, care or treatment. Over 650 delegates attended including doctors, nurses, pharmacists and scientists.

“The conference was an excellent experience for me,” said Dr Taylor. “It was packed full of educational and interesting talks. I presented an idea for a clinical trial for the treatment of people with mesothelioma, to an audience of about 250.

"I had not stepped onto a podium in front of such a large number of people before, and to my surprise I did not feel too nervous beforehand! I was very pleased to make contacts that will enable me to progress the trial...

Dr Taylor also presented a poster, describing her review of how people with mesothelioma in South Yorkshire responded to chemotherapy and what side effects they had.

(Pictured left) Dr Fiona Taylor Clinical Research fellow in medical oncology

Lily presents to South African conference

Third year PhD student Lily Oguh is researching new therapeutic strategies to manage malignant pleural mesothelioma at the University of Hull. She attended the world’s most important mesothelioma conference, The International Mesothelioma Interest Group, with a travel award from the Fund. The conference was hosted at the stately Cape Town International Convention Centre in the beautiful rainbow city of Cape Town in South Africa last October.

“A wide range of topics were discussed, with sessions on surgery, epidemiology, molecular biology, immunology, novel therapeutics and so much more,” said Lily. “I was fortunate to listen to talks from seasoned researchers like professors Michele Carbone, Dean Fennell, Bruce Robinson, Hedy Kindler, van Meerbeeck and others. I also had the opportunity to meet Laurie Kazan-Allen, one of the patrons of the June Hancock Mesothelioma Research Fund and a real force for change in the global fight against asbestos.”

Lily also presented some of her own PhD work on the over expression of lipooxygenases (enzymes promoting inflammation and carcinogenesis) in mesothelioma tissue samples and the effect of some newly developed compounds on mesothelioma cells.

“I had the chance to network with scientists from different research groups in various parts of the world. It was indeed an intellectually stimulating conference.

More feedback from recipients of JHMRF awards...

Contact us

Write to us or send donations to:
The June Hancock Mesothelioma Research Fund
Riverside East, 2 Millsands,
Sheffield S3 8DT

Please make cheques or postal orders payable to “The June Hancock Mesothelioma Research Fund”.

If you are a UK taxpayer living in this country please include a Gift Aid Form so that the Fund can reclaim the tax. (Gift Aid forms available on request).

Donating online

It’s easier than ever to register your fundraising event online, or to make a donation to someone you know who is registered and raising money for the Fund. Here’s how:

Just Giving – simply log on to www.justgiving.com

CAF (Charities Aid Foundation) – simply log on to www.cafonline.org

Donations can be made securely online, which makes this a great way of collecting sponsorship money for your fundraising events.

Help us by:

○ Adopting the Fund as your “Charity of the Year” if you are a business or corporate donor

○ Making a Gift Aid or tax efficient donation

○ Setting up a monthly direct debit or standing order donation

○ Organising your own fundraising event

○ Registering your fundraising event on Just Giving www.justgiving.com or CAF www.cafonline.org

○ Making an endowment or leaving the Fund a legacy

Sponsorship forms can now be downloaded from www.junehancockfund.org

The Fund welcomes all donations large and small to support its work in memory of June Hancock.

Donating by text

Donate by text for free. Simply text JHMRF00 and the amount you wish to donate (You can donate either £1, £2, £3, £4, £5 or £10) to 70070. Your text will look something like JHMRF00 £5.