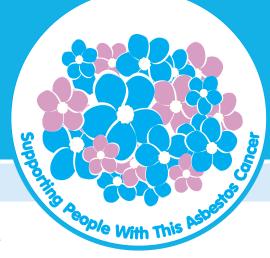
Mesothelioma UK Newsletter

Summer Issue 2013



Forthcoming Events for Health Professionals

British Thoracic Society Summer Meeting 2013

> 13 - 14th June 2013 Manchester www.brit-thoracic.org.uk

Mesothelioma Study Day

4th July 2013 London Bridge Email Sarah.compton@gstt.nhs.uk or Rachel.c.thomas@gstt.nhs.uk

> World Lung Cancer Conference 2013

27 - 31st Oct. 2013 Sydney, Australia www.2013worldlungcancer.org

9th NCRI Cancer Conference

3 - 6th Nov. 2013 Liverpool www.ncri.org.uk/ncriconference/

Advances in the Diagnosis and Treatment of Lung Cancer

21st Nov. 2013 The Royal Marsden Hospital, London

NLCFN 15th Annual Conference

28 - 29th Nov. 2013 London www.nlcfn.org.uk

British Thoracic Society Winter Meeting 2013

4 - 6th December 2013 London www.brit-thoracic.org.uk

BTOG 12th Annual Conference

29 - 31st January 2014 Dublin www.btog.org

Dear Meso UK Supporter

Welcome to the summer edition of Mesothelioma UK's Newsletter. I am delighted to announce that thanks to our many fundraisers and sponsors Mesothelioma UK will this year financially support the appointment of two more Mesothelioma Clinical Nurse Specialists (MCNS) in Portsmouth and Manchester, bringing the UK total to 5.

Several other centres expressed an interest to host a MCNS and providing our funds continue to grow we will seek to increase this invaluable body of nurses.

Mesothelioma UK now receives approximately 150 helpline contacts and 2500 website hits per month. Last year we circulated 6800 hard copies of newsletters. We are holding a Stakeholder Event in Leicester on June 24th and would encourage anyone interested in helping shape the future of Mesothelioma UK to come along and contribute.

Several students have just finished the most recent Mesothelioma Practice in Cancer Care module through the Royal Marsden School of Nursing meaning 45 health care professionals have now finished the course. In addition any health care professional can join the Mesothelioma UK Community of Practice, an online community for those interested in mesothelioma that provides a variety of resources to support clinical practice, not

least a communication network with like minded people. Contact Mesothelioma UK for more information about each if you are interested.

News about clinical trials is encouraging with MESO 2 on the cusp of opening, SKOPOS now actively recruiting, MARS 2 also has funding and the protocol is in final stages of development and the UK Meso/VATs study about to report – watch this space!

We will shortly be circulating our Annual Action Mesothelioma Day Bulletin to interested groups, please start to plan your events and let us know what you will be doing so that we can advertise for you.

We are always happy to receive your news and views, keep sending them in.

Liz Darlison

Macmillan Mesothelioma Consultant Nurse

Updated Patient Information

Our Mesothelioma UK patient information is currently being updated and should be available very soon in the new blue 'Forget-Meso-Not' format.

All the medical information contained in these factsheets has been reviewed by the author and amended where necessary. As soon as these new factsheets are completed they will be available to order in hard copy or to download from our website: http://www.mesothelioma.uk.com/patient-information.htm.

Please keep a look out on our website for the new ones which will be coming soon.

Tracey Heseltine Mesothelioma UK

Information Prescription Delivery Service (IPS)

Most people affected by cancer want to be able to understand their situation and have a sense of control over their lives. Patients who are well-informed, experience less anxiety, take a greater part in their treatment plan, and are better equipped to cope with their illness than those who are ill-informed or uninformed.



National Cancer National Cancer Action Team (NCAT) launched Cancer Research

UK, Macmillan and other smaller charities, including Mesothelioma UK to help provide consistent and accurate advice to cancer patients throughout the country.

The main aim of NCAT was to develop a web based Information Prescription Delivery Service (IPS). The IPS housed for each cancer type, an "Information tailored to their needs.

Mesothelioma UK has worked hard recognised as experts in their

As a result of this, and after rigorous Department of Health checks, Mesothelioma UK was awarded the Accreditation" - the "Gold Standard Kite Mark", which certifies the holders are

reliable producers of health and social care information. We are very proud to have achieved this recognition. The NCAT contract came to an end in by the Government. The IT services firm, Capita, has had very publicised disagreements with NHS choices and their contract runs until November 2013 is indeed uncertain.

At an emergency meeting for Stakeholders of the Information Prescription Service on Monday 22nd April, plans were made to deliver a collaborative voice to write to the All expressing our deep concerns. Our aim is to ensure that all our hard work is not that patients across the UK receive the information they require and deserve.

factsheet. Your comments would be

Gerry Slade

Mesothelioma UK Nurse Specialist

The Mesothelioma **Applied Research** Foundation (MARF) 2013 Symposium

I was fortunate again this year in March to be invited by the wonderful MARF team to attend and present at their annual symposium.

MARF is the US national organisation dedicated to providing support and information and finding a cure and eradicating mesothelioma as a life-ending disease. The work of the Foundation is funded by mesothelioma patients and their families who have invested generously as well as law firms, drug companies, and companies formerly involved with asbestos, all of whom have joined in the common mission of curing the disease and eliminating the risks of asbestos exposure.

Previously all presentation from the symposium have been posted on the foundations website www.curemeso.org. In addition this year the whole meeting was livestreamed on Facebook allowing people all over the world to be involved. Several UK patients and carers we connected and they contributed to the guestion and answer sections. My report about the MARF 2013 symposium can be found at http://www.mesothelioma.uk.com /clinical-trials.htm

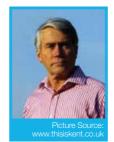


Above: Laptop in the foreground demonstrating the live streaming of the presentations via Facebook as they happen



Education Select Committee Hearing into Asbestos in Schools

On 13th March the Education Select Committee held a hearing into asbestos in schools. Evidence was given by the Schools Minister David Laws MP, David Ashton a director of HSE, Professor Julian Peto a leading epidemiologist, Julie Winn the Chair of the Joint Union Asbestos Committee, Roger Leighton a headteacher and Michael Lees a member of the Asbestos in Schools Group.



The Committee heard that a report by the Medical Research Council concluded it is not unreasonable to assume that the entire school population has been exposed to asbestos in school buildings

and that the exposure may constitute a significant part of a lifetime exposure.

Professor Peto stressed the increased risk to children from asbestos exposure "The risk keeps going up...once you have been exposed to asbestos, the risk goes on increasing for the rest of your life. It increases very steeply after a very long latency...It is reasonable to say that something of the order of 100 or 150 deaths per year from mesothelioma in women could in the future be due to asbestos levels in schools up to the 1960s and 1970s." If there are a similar number of deaths in males it would mean that up to 300 a year could die because of their asbestos exposure as a child at school.

The Minister and Mr Ashton reiterated that the Government's policy is to leave asbestos in place and manage it until the remaining life of the buildings, as they consider that is safer for the occupants. They do not consider that it is the Government's responsibility to know the scale of the problem and have therefore specifically excluded asbestos from the audit of the condition of school buildings. They have also cancelled inspections to determine the standards of asbestos management in local authority schools because HSE advise that the risks are very low. Julie Winn and Michael Lees gave evidence that the policies are not working.

The Minister confirmed that the Government will carry out a review of their policy towards asbestos in schools once the Committee on Carcinogenicity publishes its report on the relative vulnerability of children to asbestos following their meeting on 9th May.



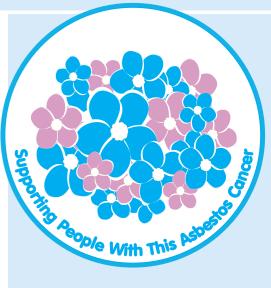
Transcript of hearing: http://www.publications.parliament.uk/pa/cm201213/cmselect/cmeduc/c1056-i/c105601.htm Video of hearing: http://www.parliamentlive.tv/Main/Player.aspx?meetingId=12840 Written evidence: http://www.publications.parliament.uk/pa/cm201213/cmselect/cmeduc/writev/1056/contents.htm

New Initiative to Support Patients as Research Ambassadors in the NHS

The NIHR Clinical Research Network has launched Involvement4Access. a resource for the research community, which contains guidance and examples of best practice on how to engage and empower Patient Research Ambassadors.

Many patients and carers are already Patient Research Ambassadors. They feel passionate about research and are prepared to talk about it, both with each other, and NHS care professionals and managers.

To find out more about this resource please go to the website below: http://www.crncc.nihr.ac.uk/ppi/why_is_research_important/involvement4access



BLF and MKMRF Mesothelioma Survey

The British Lung Foundation, in partnership with the Mick Knighton Mesothelioma Research Fund conducted a survey of 240 patients and loved ones of those living with mesothelioma with the help of Mesothelioma UK during March.

The topics covered included experiences of: Diagnosis, asbestos exposure, welfare benefits, the legal process, medical care and some demographic questions. A majority of those who responded to the questionnaire were a family member, and half of those who had been diagnosed with mesothelioma were young at between 51-65 at diagnosis. It appears the largest occupation given for the person with mesothelioma was an electrician at 15%.

Most of those surveyed made a claim for compensation, and when asked about improvements to the claims process, the main area suggested was to speed up the claims process taking into consideration the distress the family is already going through.

When respondents were asked what single thing could make the biggest difference to people living with mesothelioma, for 77% it was continued research to find a cure. We hope the report's insight will be invaluable in making sure that the Government and decision makers take account of the experiences of people living with mesothelioma and their families in the coming months, as changes to the legal claims process are discussed.

Thank you to all those who took the time to fill out the survey and share your experiences, the full report is expected to be available to download from the Mesothelioma UK website at the end of May.

Jo Kaye BLF

Our First Patron

Mesothelioma UK Charitable Trust is delighted to announce our very first Patron. Kierston Wareing is an actress currently starring in Eastenders as the character Kirsty Branning. Kierston sadly lost her mum to Mesothelioma last year and the Mesothelioma UK charity is very close to

her heart. Kierston will be attending the 2013 Patient and Carer Day which takes place on 5th October in Leicester.

Mesothelioma Newsletter - Summer Issue 2013

The Perils of Asbestos

Over the last two decades or so, campaign groups have used the digital world to shape public opinion. You only have to look at the power of social media sites such as Facebook and Twitter, to see how our desire to find the next big thing means certain issues fall by the wayside. Asbestos and its related disease mesothelioma is one of those issues.

and the picture was very different. Back then asbestos was commonly used as a building material and insulator in shipbuilding, homes, gardens ornaments and even Artex for ceilings. It was not until the mid-80s that the industry to asbestos and in turn ordered the safe removal and disposal of asbestos from business premises. This is still a major £1m in 2011 for putting their staff at risk.

Even properties constructed in the last 10 years can fall victim to asbestos Medway, Kent. The former shipbuilding area of the Chatham Dockyard closed twenty years ago but was known among locals as a dumping ground for asbestos.

Monfalcone in North East Italy is another

The booklet, "lo sono Cantieri" (translated roughly as the yard inside me), tells the story of how a local group from Monfalcone turned things around.

stories written by ordinary people afflicted by mesothelioma, but also has contributions from medical and health care professionals. There is even a murder mystery. It recounts how their pressure forced the fiscally-challenged local government to set up screening facilities, give grants to private residents so they could remove asbestos safely.

Through all this research work, the group came to the realisation that asbestos is a global issue. As well as collating but by working in harmony they hope to spread this message: "is the life of a Bangladeshi ship-worker forced to handle asbestos, for a piece of bread. knowing it could kill him, worth less than his counterpart in the West?" #

#Davide Stanic (2011) io sono cantieri Fuorilinea Rome page 69.

Patrick Bryant

to inform readers when the translated version of "lo sono Cantieri" is available in English.

Applications Open for WCLC 2013 Advocacy Travel Awards

The International Association for the Study of Lung Cancer (IASLC) invites patient advocates to apply for the organization's Advocacy Travel Awards.

The IASLC will offer travel awards to a limited number of patient advocates to participate in the World Conference on Lung Cancer Oct. 27-30, 2013 in Sydney, Australia. Awardees receive free conference registration, up to four nights' accommodations, a free IASLC Membership and a cash award for 1,000 AUD. The IASLC will award up to five travel awards. All applicants must be current members, but Advocates can join the IASLC for just US\$50. Fewer than five may be awarded.

Full details regarding the application process and eligibility selection are available on the WCLC Website:

http://wclc.iaslc.org/scientific-program/scholarships.html#AdvocacyAwards

The submission deadline is 21 June 2013.

Mesothelioma **Research Grant Funding**

The Mesothelioma Applied Research Foundation (Meso Foundation) is calling for applications for its 2013 round of mesothelioma research grant funding

The Mesothelioma Applied Research Foundation offers research grants for two years up to \$50,000 per year. Eligible projects may relate to benchwork, translational or clinical research that is not presently funded or pending review and may be conducted through any notfor-profit academic, medical or research institution. The Foundation will review and monitor the project's progress and results, requiring semi-annual disposition of funds reports, a ten month progress report, a presentation at the Foundation's Symposium and a full progress report at the close of the project. The Foundation seeks exceptional projects for which the Foundation's funding is demonstrated to be essential and not duplicative. Please be advised that the Foundation does not pay institutional indirect costs.

Funded researchers will also be entitled to facilitated access to the National Mesothelioma Virtual Bank (NMVB), www. mesotissue.org. They will receive expedited review of requests to use the NMVB, and they will have direct, no-cost access to materials in the bank, as well as enhanced collections from the main sites of materials.

Encouraged projects include, but are not limited to, investigations of:

- 1. Strategies for early detection of new or progressive disease;
- 2. Definition of targetable differences between normal and transformed mesothelium and development of novel strategies for treatment;
- 3. Therapeutic intervention, including but not limited to:
- a. Immune Response Targeted Therapy b. Novel chemotherapeutic compounds
- c. Novel radiation or surgical techniques
- 4. Determination of clinical/molecular determinants for prognosis

Applications should be submitted through https://proposalcentral.altum.com/ default.asp?GMID=94. You will find the Mesothelioma Applied Research Foundation listed with the instructions and the application required. Applications are limited to 10 pages (not including biographies) and are due no later than 2 August 2013. Final award decisions will be made in December 2013 and all applicants will be notified of the outcome.

SKOPOS: A Phase II Study of TroVax® in Mesothelioma

Velindre Cancer Centre in Cardiff has recently opened a small phase 2 trial to assess the safety and immunological activity of the vaccine TroVax® in combination with first-line Pemetrexed and cisplatin chemotherapy in patients with malignant pleural mesothelioma who have not previously had chemotherapy for their disease.



The study is funded by the June Hancock Mesothelioma Research Fund, the Velindre Cancer Centre Stepping Stones Appeal, and Oxford BioMedica has provided the vaccine

TroVax® is a therapeutic vaccine that stimulates the immune system to destroy cancerous cells expressing the 5T4 protein (or antigen). Research carried out by Dr Zsuzsanna Tabi at Velindre Cancer Centre has shown that the 5T4 antigen is widely present on mesothelioma cancer cells. The 5T4 antigen is not found in any significant level on normal non-cancerous cells. TroVax® is based on an attenuated vaccinia virus engineered to deliver the 5T4 antigen into the body. An attenuated virus is one that has been altered so that it becomes harmless or less virulent; commonly used attenuated viruses include measles, mumps and rubella vaccines.

In order for TroVax® to be effective, it needs to induce an immune response in the body against the 5T4 antigen. The immune system will then attack any mesothelioma cancer cells expressing the 5T4 antigen. The main aim of the study then, is to establish whether TroVax® does induce an immune response against the 5T4 antigen in patients with mesothelioma. We will also be looking at other measures of clinical benefit including safety, the proportion of patients responding to treatment, and survival.

We know from previous trials in other cancers that TroVax® is safe and well tolerated and can be administered in combination with chemotherapy. Side effects from TroVax® are mild and include fatique, chills, fever and injection-site reactions.

We aim to treat a total of 26 patients with a combination of chemotherapy and TroVax® in the study. Patients will receive 9 TroVax® injections given over a 24-week period in addition to their chemotherapy. Regular blood tests will be carried out to measure the patients' immune response to the vaccine. If the study shows that TroVax® is effective at stimulating the immune system to mount an anti-cancer immune response, TroVax® will be tested in a larger clinical trial. Dr Jason Lester

Dr Jason Lester



Move it or Lose it!

Julie Robinson, owner of Move it or Lose it! is on a mission to make fitness fun and available to everyone (even those who don't like exercise)!



Some of you who attended the Mesothelioma UK Patient and Carer Day in 2011 may remember Julie's presentation.

Having won the National Diversity Award as Entrepreneur

of Excellence in the Age Category last year, Julie has now started writing a regular Q&A column for national magazine Yours to help people who want to stay mobile but aren't sure how to do it. Julie says "Just by increasing your level of activity a little every day can help to make a difference and most of the exercises can be done sitting down."

Move it or Lose it! has become a collaborating partner in The Centre of Excellence for Musculoskeletal Ageing Research at University of Birmingham which aims to understand how ageing results in loss of strength and function and to use this knowledge to minimise decline through exercise and other lifestyle changes.

Julie is now working on a series of new DVDs to help people who prefer to workout at home, which will focus on maintaining independence and mobility.

"I regularly teach exercise classes for people with life-limiting illnesses and know how difficult it is to motivate yourself especially when you feel fatigued all the time. By adapting exercises to be done from a chair and offering gradual progression, it's amazing how much people can achieve."

For regular updates and tips sign up to Julie's email at www.moveitorloseit.co.uk

If you would like to write an articlé for our next newsletter due out in August please contact us on:

0800 169 2409

or email mesothelioma.uk@uhl-tr.nhs.uk

Patient/carer stories are particularly welcome.

Mesothelioma Newsletter - Summer Issue 2013

Best Foot Forward

If you are living with or after cancer and want to make a positive change to your life, being more active could be the answer. But this doesn't have to mean running a marathon.



Physical activity varies from day to day fitness classes at the gym. There are lots of ways you can begin to get more active.

At Macmillan Cancer Support we know even small increases in physical activity can improve your quality of life. Described as a 'wonder drug' for people living with is safe to do and has lots of benefits including helping you manage the side effects of treatment such as fatigue, stress and anxiety. It has also been shown to improve muscle and bone strength and reduce depression.

If you live in England, why not go along to your nearest Walking for Health group? Run by Macmillan and the Ramblers, you can take part in a free short walk nearby to help you get active and stay active at a pace that works for you. It's a great way to To find your nearest walk visit www.walkingforhealth.org.uk.

Similar schemes operate in

Alternatively if you would prefer to get active at home, Macmillan offer a range of free resources to help you get started. You can order your Get Active Feel Good copy of Get Active Feel Good exercise to music DVD (available from 26 June) from

For more information visit macmillan.org.uk or call our Macmillan Support Line free on 0808 808 00 00 (Mon-Fri 9am-8pm)

Bristol and Beyond Asbestos Family Support Held Their Annual Patient Conference

Members enjoyed a day of informative, positive presentations, lots of chat and laughter, good food and a saunter around Bristol Zoo for those that fancied it when we met on 8th March.

This is our third annual conference and it was heart warming to see how numbers have grown over the years and at this event we were thrilled to welcome over 60 people. New friendships were made and others greeted those who had already become firm friends. Members had generously donated lots of raffle prizes, so many left with gifts and the group raised over £150 to cover the running costs of the BBAFS website. We also presented a gift and card to Pat and Tony, two of our members and wished them every happiness for their wedding on 25th March.

It really is a special group and we welcome members from a very wide area, just telephone Rachael Wilson on 07544 213475 if you have any gueries.

Here are some of the interesting things we learned during the day from our great

Dr Nick Maskell, Consultant Respiratory Physician, North Bristol **NHS Trust "Cycling for Trials"**

• It is difficult to diagnose mesothelioma but that there are world class Pathologists in Bristol and they have developed ways of getting the best tissue to ensure the diagnosis of the disease needed to be robust and correct.

- There is a regional meeting where every case of diagnosis is discussed.
- · Dr Maskell is working closely with the Bristol Coroner, Maria Voisin, on a trial so that where patients have been diagnosed with mesothelioma during their life time and have a history of asbestos exposure then the need for a Post Mortem is dispensed with.
- There are more asbestos related search trials in the Bristol area than in any other centre in the UK.
- Currently there are 5 UK studies currently open. These include the SWAMP, SMART, ZA trial, IPC Plus and TAPPS trial.
- There will soon be a PET scanner in Bristol. This is a great step forward as currently mesothelioma patients in the Bristol and surrounding areas have to travel to Cheltenham for PET scans.
- In the Bristol area chemotherapy is offered to all patients whereas in some areas of the country chemo is not offered to those suffering from sarcomatoid mesothelioma.
- Nick told members about the Avon Mesothelioma Foundation which has raised £50,000 so far to provide equipment and to support research in



Picture Source: www.bristolasbestossupport.co.uk

- · Nick then showed us slides of his last cycling trip in which he had raised money for the Avon Mesothelioma Foundation.
- The foundation is now looking to raise £200,000 to buy a new ultrasound for the department. Nick has now set himself a new cycling challenge which he aims to complete on 6 June 2013. If you would like to sponsor Nick or donate to Avon Mesothelioma Fund then follow this link:http://www.avonmesothelioma foundation.org.uk/for-donors-andsupporters/

Karen Gough, **Macmillan Benefits Adviser**

Karen gave us an overview of how benefits were going to change after April. She told us that Attendance Allowance will stay the same for those over pension age but for those under pension age the new Personal Independent Payments (PIPs) will be brought in. The assessment criteria for PIPs will be stricter and individuals will be required to attend at a medical. Benefits are a very complicated area and those suffering from an asbestos related disease and as well as their families should if at all possible seek specialist advice.

Jo Barnes-Manning, AASC

Jo shared her experiences of setting up an asbestos support group in Wales following the sad death of her father to mesothelioma.

She also told us a little bit about the new Asbestos Bill which is progressing through the Welsh Parliament. This is an exciting development as potentially it will mean that the NHS costs of those suffering from asbestos related diseases could be recovered from the guilty exposing party.

Sarah Smith, Lung Cancer Specialist Nurse, Southmead Hospital

Sarah told us about lifestyle workshops that she runs for patients at North Bristol NHS Trust. She would like this to be part of a national initiative to reduce anxiety amongst patients. Sarah has entitled these workshops "Know More Do More" days with the philosophy that patients and carers should be armed with as much information as possible.

The purpose of these workshops is to:-

- Reduce out-patients symptoms which tend to be raised shortly before clinic.
- Help reduce the anxiety caused by not having regular appointments
- Answer questions and to try to get patients back to normality.

- Have advice available from specialist nurses as well as physios and dieticians.
- Provide an opportunity for carers to meet other carers.

Walking for Health

There is an initiative "Walking for Health" which has been set up with Bristol City Council as even when a person is ill there are benefits to be had from exercising. There is an opportunity to meet weekly in Fishponds for a stroll which is also suitable for wheelchair users which finishes with tea and cake.

Natalie Brady, Somerset Cancer Care

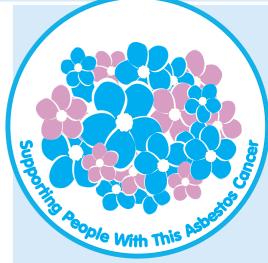
Natalie is based at St Margaret's Hospice in Taunton and is also supported by Macmillan. Natalie described how she arranges support groups for families affected by cancer in Taunton, Minehead, Wells, Weston Super Mare and Yeovil. Somerset Cancer Care can be contacted at St Margaret's Hospice 0845 070 8910 / @SomersetCancer / www.stmargaret's-hospice.org.uk

Professor Robert Thomas, Chair of the Macmillan Expert Exercise **Advisory Committee and a Consultant** Oncologist at Bedford, Addenbrookes Hospitals and at Cranfield University Professor Thomas spoke to us about self help and lifestyle strategies after cancer.

- Professor Thomas described that we are genetically programmed as to whether or not we develop cancer during our lives.
- We can take positive active steps to:-
- Change our lifestyle
- To reduce side effects
- To slow the growth
- To reduce our chance of relapse
- To improve our chances of survival.

Some of the positive things we can do are:-

- Take 3 hours of exercise each week.
- Ensure our diet contains oily fish and fish oils.
- As effective ways of keeping our bones healthy and get calcium in by including pulses, lentils and quiona.
- · Anti-cancer foods are minerals and vitamins and secondly polythenols (previously known as anti-oxidants).
- . Most of us in the UK are deficient in Vitamin D.





- Long term vitamin mineral supplements are not recommended, it is only necessary to take a vitamin to correct a known deficiency.
- If we were to take any supplements then Vitamin D and fish oil were most important.
- Great foods to eat for maximum health are pomegranate, green tea extract, prunes, raisins, turmeric, herbs, spices, teas and broccoli.
- Wild blackberries (if you are able to get out and pick them) have far more nutrients than shop bought blackberries.

For more information about cancer, or to see the research conducted by Professor Robert Thomas and the research team at Bedford Hospital you can visit

www.cancernet.co.uk or read Professor Thomas' book "Lifestyle and Cancer".

Professor Thomas has been involved in trials of the food supplement POMI-T and prostate cancer. POMI-T contains pomegranate, broccoli, turmeric and green tea.

More information can be found at www.pomi-t.com



Email bristol_and_beyond@yahoo.com

Action Mesothelioma Day 5th July 2013

Mesothelioma UK and the Derbyshire Asbestos Support Team will again be joining forces to host the Leicester Action Mesothelioma Day, 'Reflection and Celebration of Life' to be held at the Leicester Cathedral.



Even though the weather was terrible last year with rain storms the Reflection was very well attended with nearly 150 people turning out to remember those who are no longer with us and for those who are living with mesothelioma. The cathedral will be open from 3.00pm so please bring your message roses to be placed on the trees of reflection.

The Reflection will start at 3.30pm ending with a Dove release followed by refreshments. As part of the Reflection and Celebration of Life the names of those who have fallen victim to mesothelioma will be scrolled on a screen inside the Cathedral. If your name or that of a loved one appeared on the scroll last year, there will be an automatic inclusion this year unless you inform us otherwise.

If your name or the name of a loved one was not included but you would like a name included on the scroll for Action Mesothelioma Day this year then please contact either Jill Lemon at Mesothelioma UK 0800 169 2409 or Joanne Gordon at the Derbyshire Asbestos Support Team 01246 380415. Message roses will be available at the cathedral on the day.

There will be many organised Action Mesothelioma Day events held around the country and smaller individual events, and if you would like to email us the details we will put it on the Mesothelioma UK website and in our Action Mesothelioma Day Bulletin. Please email details to mesothelioma.uk@uhl-tr.nhs.uk or ring us on our freephone helpline 0800 169 2409.

Mesothelioma UK Patient/Carer Conference

Meet other people affected by the disease, listen to national experts and hear about self help opportunities.

Saturday 5th Oct. 2013 Mercure Leicester City Hotel, Granby Street, Leicester, LE1 6ES

Check our website

www.mesothelioma.uk.com

nearer the time for details of how to register or Freephone 0800 169 2409

Free to patients and carers – donations accepted

Mesothelioma UK Stakeholder Day

Monday 24th June 2013

Glenfield Hospital Clinical Education Centre, Leicester LE3 9QP

Patients/carers wanted to attend the day to help shape the future of Mesothelioma UK. Places are limited so please let us know as soon as possible if you are interested in attending on freephone 0800 169 2409

Mesothelioma UK Nurse – Wales (Update)

I have been in post since February 2013. It is proving to be a very daunting, but exciting development.

My brief for the next two years has three components: focusing firstly on the local nursing service provision here in Cardiff and then influencing and informing the shape of the mesothelioma



services across South Wales to deliver a regional and national framework.

Within Wales we have a well developed network of lung cancer nurses (22 in total) all of whom are often introduced as the 'key worker' when a diagnosis of mesothelioma is given.

My intention is to ensure that all Welsh Lung Cancer Specialist Nurses are involved in ensuring the information provided within their local area is relevant, easily accessible and current through our network. The resources developed by Mesothelioma UK are key to this.

There has also been an identified need for the development of a support group as currently mesothelioma patients from the whole of South Wales travel to Bristol to access this support. The vision is that we are able to establish two across the region, one in the South West (venue to be decided) and one in the South East (Cardiff/ Barry).

"The launch of the support group in Cardiff is currently planned for September."

It is becoming more evident that the patient and carer voice is not heard effectively without something of a battle and it has been noted that meeting with like minded people will strengthen this and be another forum for sharing information.



The Mesothelioma Bill

The Mesothelioma Bill has commenced in the House of Lords. This Bill seeks to remedy the historic failure of insurance companies to maintain records of employers' liability insurance. This failure has meant that those suffering from long-latent diseases, whose employers are no longer trading, and who have been unable to trace their insurers, have for decades gone uncompensated.



Image courtesy of www.independent.co.uk

Asbestos Victims' Expectations for a Bill

This Bill is the culmination of two years' Coalition Government negotiation with insurers following Labour's consultation in February 2010. The main consultation proposal was for an Employers Liability Insurance Bureau, which, like the Motor Insurance Bureau would provide an insurance fund of last resort to pay full compensation for all those who could not trace their insurer and who could prove employer negligence.

What the Mesothelioma Bill Provides

The Bill provides for an administrative 'tariff' scheme which pays average compensation based upon age to mesothelioma sufferers who cannot trace their insurer and who can prove negligence to the standard required by civil law. The average payment will be reduced by approximately 30% and will be funded by a levy on active insurers. Payments may be made to dependants if a claim is not made in life. Mesothelioma sufferers diagnosed after 25 July 2012 will be eligible to apply for a payment.

Asbestos victims excluded

The Bill excludes all asbestos victims other than mesothelioma sufferers, yet, including them in the scheme would represent just 20% of the total cost. The Bill also excludes all mesothelioma sufferers who were diagnosed prior to the 25 July 2012.

When will payments be made?

Payments will be made after the Bill has passed through all its Parliamentary stages, which should be about April 2014.

Reactions to the Bill

We have welcomed the Bill as a first step. But we are bitterly disappointed that so many people are excluded from the scheme. We are particularly concerned that mesothelioma sufferers will lose 30% of their compensation. The reason the Government gives for the reduction is that mesothelioma sufferers must have an incentive to trace the insurer. In fact, they have every incentive to trace an insurer because if they do succeed they will get compensation based on their individual circumstances, and not just an average payment. It is insurers who have everything to gain if claimants are paid under the scheme: they stand to save a lot of money.

What can be done to improve the Bill Now is the time to say how you think the Bill should be improved. The Bill is written in such a way that it cannot be amended to include all asbestos victims. But, there are other changes that can, and should be made. You can contact your MP and we would very much like to receive your comments so that we can pass them onto members of the House of Lords. Our contact details are on our website: wwww. asbestosforum.org.uk . We would love to hear from you.





"Tony Whitston recently retired from Greater Manchester Asbestos Victims Support Group. We would like to wish Tony all the best in his retirement. although he will be remaining with GMAVSG in the role of Trustee. Many thanks Tony for all the help you have given us over the years" – from the Mesothelioma UK Team.



GMAVSG and Chair of Asbestos Victims Support Groups Forum

To Run Mesothelioma UK for 1 year £310,000 is required!

Mesothelioma Newsletter - Summer Issue 2013

Mesothelioma Newsletter - Summer Issue 2013

Mesothelioma Newsletter - Summer Issue 2013

Mesothelioma UK Charitable Trust 1126083

Fundraising News

The East Hull under 13's Team and their wonderful Mo's - written by Russell Jones

On a freezing cold March morning East Hull U13s rugby league team were getting themselves ready to play a game against local rivals Hull Dockers. However pre-match preparations were somewhat unusual when both sides sported moustaches in aid of Mesothelioma UK Charitable Trust.



Parents and supporters on both touchlines welcomed the fundraising and this became more apparent when three people said they had lost friends to The collection had even more meaning now! The game played in good spirits it was East Hull coming out on top leading 40-nil before a serious injury caused the ref to call time on the game. Thankfully the youngster in question is now home recovering with no lasting issues. I would like to thank Bridge McFarland Solicitors who sponsor East Hull U13s and who helped me to set up the event. Finally thanks to everyone who generously supported the day by popping money into the collection.

Moustaches For Meso In March 2013

This year, chaps and even the girls in the Industrial Disease team at Boyes Turner solicitors have been taking part to show their support. Here are some wonderful pictures of their moustache growing progress, or lack of it!!



Moustaches for Meso day 12 diary

"12 day's into growing my moustache and things have become increasingly difficult. There is the constant itch on my upper lip, the strange reflection staring back at me in the mirror and the feeling that I need to explain the tufts of hair that protrude from my face to everyone I meet. But I can deal with the physical discomfort, what affects me more is the sense my moustache is simply inadequate, especially when compared to my fellow colleagues.

I have become ashamed of my moustache despite all that it stands for and despite the knowledge that there is a real need to raise awareness for the most deserving of causes. The idea of not shaving for a month hardly seems like an ordeal and yet, the constant shame and sense of inadequacy about my mo, raises this to an emotional challenge. I shall persevere and gain strength from others. I will fight on in the hope that tomorrow I will wake with a fuller, bushier 'tash." - Mark (aka Mr peach fuzz).

The Boyes...The end result...Perfecto...



Rock and Roll Concert Dinner in Aid of Mesothelioma **UK**, Written by Clare Holloway

Martin Wodehouse was diagnosed with mesothelioma in 2010 and since then has been organizing events and fundraisers with his merry band of helpers to help raise money and awareness for Mesothelioma UK.

This March Martin's wife Lynda organised a rock and roll evening at The Dorking Halls in Surrey. The evening was presented by BBC Radio Surrey's Mark Carter and included a 2 course dinner, a raffle drawn by Mole Valley's Councillor Salmon with over 30 prizes donated from local businesses and organisations, a fantastic performance from West End star Billy Geraghty and his rock and roll band & there was even a personal tribute to Martin from Lynda who sang 'You'll Never Walk Alone' along with their son's girlfriend Clare and friends from the Dorking Rock Choir.

Lynda & Martin would like to thank the front of house and technical crew at The Dorking Halls, Councillor Salmon, Mark Carter, Billy & the band for all their support on the night and to all those who were involved or came to support it. The night was greatly enjoyed by all and achieved its goal in raising awareness for the charity.

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

In this Issue:

- Fundraising Update
- Our Fab Fundraisers
- Action Mesothelioma Day
- Picture Board

Moustaches for Meso in March 2013

Our supporters just get better and better, young and older alike they are just fantastic...we have seen some wonderful moustaches either grown or worn to support this special month and the Mo is growing and we hope nationwide.

Chris Knighton from the Mick Knighton Mesothelioma Research Fund and Joanne Gordon from the Derbyshire Asbestos Support Team feel they want to help spread the word far and wide and have decided to join forces with Mesothelioma UK next year and encourage all their supporters to grow or wear a 'Moustache for Meso In March' which we think is wonderful.

People will sit up and take notice the more we bring it to the public's attention so if you want to come and join us 'we say the more the merrier'.

Phil Tuffnell -**Celebrity Pointless**

Phil Tufnell former England cricketer spin bowler and team captain on A Question of Sport, and 2003 winner of I'm a Celebrity get me out of here' on Saturday 16th February appeared on 'Celebrity Pointless' and went on to win the competition with his partner Martin Offiah.

Phil very kindly chose the Mesothelioma UK Charitable Trust as his chosen charity which is just a fantastic boost for all those people suffering with mesothelioma. It is wonderful to hear a popular television star mention our charity and recognise this dreadful disease.

Phil kindly donated his winnings of

£1,250.00 which is just brilliant.

The Pannone **Super Heroes**

City centre law firm, Pannone are always on the side of justice but when they're joined by superheroes like Batman, Spiderman and Superman, the bad guys don't stand a chance!



In fact the caped crusader and his chums were all Pannone employees, raising money for Mesothelioma UK.

The superheroes were taking part in a treasure hunt organised by Rachel Craig and Lynsey Robinson from the firm's Serious Injury department, which deals with asbestos related cases.

The hunt involved participants finding clues, which took them around bars in Manchester, to find the bad guys and save the day. Rachel Craig said "I've worked at Pannone for many years with people who suffer from mesothelioma and have seen first-hand the devastating effects it can have, not just on those suffering from the illness, but also their families." Lynsey Robinson added, "It really was quite touching to see just how many members of staff turned up to help raise money from all departments within the firm "Rachel and Lynsey raised £500.00 for Mesothelioma UK. The Winners of the 'Best Dressed Lego Superheroes' are Lisa Kelsall, Rachel Seaward, Carrie Newall, Jeremie Gayout and Yasin Bangee.

What Are Our Fab Fundraisers Up To?

The last 3 months have just whizzed by and there have been so many wonderful things going on in the Mesothelioma UK fundraising world and there are still lots more to look forward to.

There are people taking part in runs, cycle rides, treks, race nights, balls, music gigs, sky dives, you name we have it...Just amazing people!! To support any person or event, please visit our website for details or you can make a donation on-line or give us a call. Please note that when making any on-line donations you have to put in the full registered postal address for the card you are using or it will fail.

The Forget-Mesothelioma-Not Spring Ball took place on the 18th May at the Drax Sports & Social Club in Yorkshire and Anthony's Grand Summer Charity Ball will take place on 22nd June at the Thornton Hall Hotel, Torintone Suite in the Wirral tickets are £35.00 each. For more information or to book tickets contact Anna Cope at annacope@hotmail.co.uk or visit her Face Book page, Anthony's Grand Summer Ball.

It just amazes me that these wonderful people organising huge events like these seem to do it with such aplomb, style and ease which is just great and they really are fantastic, it is no mean feat to put an event like this together. So we want to thank all those lovely people who work so hard to support our charity and we hope everyone involved has a wonderful time.

Well, it's the start of the season for runners, walkers and cyclist and we have had an amazing amount of wonderful people who through blood, sweat and tears have completed their amazing challenges or they are still in the training process as their time to shine looms ever closer. Our Fab Fundraisers have also been busy organising events across the UK and overleaf is a snippet of what they have been up to!

10 **Mesothelioma Newsletter** - Summer Issue 2013 **Mesothelioma Newsletter** - Summer Issue 2013 11



Walking for Vic

beauty spot in Derbyshire. The walkers pledged to walk 20 miles for Mesothelioma UK starting from their home village of Brassington and finishing at Ashbourne on Saturday the 2nd of March 2013 The walk was in memory of a wonderful man named Vic (Witek) Andrzejewski who sadly passed away in January after a three year battle against mesothelioma.

about the walk Heather said, "Vic knew that my friends, Emily and Toni, had organised this walk and once he had passed away they asked me to join them. I've never things about the journey was that we met five people whose lives had also been affected by this devastating disease



We hoped that by doing this walk it would help raise awareness of the dangers of supported these wonderful walkers and helped them raise a fantastic £2,793.13.

Stuart Jackson

I am running for Mesothelioma UK after my father in-law was diagnosed with cancer in January. He has been a carpenter for nearly 60 years and worked with asbestos during this time. To see the effect of the illness on such a great person in such a short space of time is frightening. The money raised will help fund research and provide care, support



and information to those who suffer from mesothelioma. My first was the Brighton Marathon which I ran in April, then I will be running the New Forest Half Marathon in September, the Royal Parks Half Marathon and Great South Run in October, and I am also planning to run the Swanage Half Marathon in July when the date is confirmed and perhaps one more in June. Stuart has raised a fantastic £50.00.

Holly Hatcher

Holly decided to take part in the Brighton Marathon in April, this is what she said, "I am running in memory available". And After the race "Brighton Marathon



my friends and family who have supported me throughout the past year during what has been an extremely difficult time. I did this to help those who are suffering with mesothelioma and hopefully a difference has been made". Holly raised £2,548.76





Adam & Colin Fautley's **London Marathon 2013**

Adam took part in the London Marathon on 21st April, he took on this challenge in memory of his Grandad and this is what he has to say...

"I have been promising myself that I'd do this for a few years - now the time has come. This April, I'll be running my first London Marathon both as a personal challenge and a means to raise money for a charity which helps people who suffer with the terrible disease that took an absolute legend out of my life, My Grandad. Take it from me; the world never had a better fisherman, carpenter, West Ham fan, card player, friend and family man!

Mesothelioma is an uncommon disease that causes malignant cancer cells to form within the lining of the chest, abdomen, or around the heart as a result of exposure to asbestos. Mesothelioma UK were unable to offer me a Marathon spot as they're such a small charity, however I was lucky enough to be granted a place through the official ballot (1 in 10 chance I'm told).

This means I can create a giving page and 100% of funds go directly to the charity brilliant. I've been slogging it out over the winter in the wet, rain and snow to put me in a position to take on the challenge. A recent knee injury has set me back but that won't stop me from going for it on the day.

My dad Colin's band (www.thelateshift. org) play on the marathon route each year and they do a marathon all of their own by playing all through the day which is a fantastic way to support all the runners and they will be flying the flag this year for Mesothelioma UK. I won't need any more inspiration on the day but raising a little for this charity will really make a difference to people. That and the beer at the end will taste just that little bit sweeter"...

Adam supported by his dad Colin and The Late Shift raised a fantastic £2,293.70.

Emma Michael - My story

As many of you will know, this will be my 3rd half marathon and I hope to break the 2 hour barrier and achieve my best time vet.13.1 miles in 2 hours means really



upping my training & pace to aim for 9 min / miles or less throughout. In doing so, I hope to raise money for Mesothelioma UK. My hard work will be for my Grandad, who passed away through this asbestos related lung cancer. Although feeling exceptionally lucky & thankful to have him in my life, not a day goes by where I don't miss him and feel his time with us was cut short. I will strive to raise money for Mesothelioma UK in memory of him, to help others, and to know that each donation will give hope for the future. I feel that this particular cause of cancer charity isn't as well known as others and could particularly do with support. They help in supporting those with mesothelioma and it's treatment. Emma raised **£411.75**.

Oliver Hammond & Charles West 's Sky Dive

On the 6th of April Oliver & Charles took part in a 12,000 feet tandem skydive in hope of raising as much money as possible for their two chosen charities: Mesothelioma UK and Sebastian's Action Trust, two great charities fighting against cancer. This is what they said "We had already paid for the sky dive our selves, so rest assured all donations our wonderful sponsors gave will go directly to these amazing charities. Anything you can give will be appreciated and will help go towards eliminating cancer in our lifetime, and, until then, will improve the lives of those suffering with it". Oliver & Charles have raised £1,019.75 which is just fantastic...Well done you guys...



Nicola Bailey-Todd - Bath Half Marathon

The day of the Bathalf (Bath Half Marathon) turned out to be a relatively easy one after the

challenge, but on Christmas day my dad asked me to run tendency to go on a bit! Only setting my goal as £300.00 l was concerned that was asking too much when in fact we pockets to donate, some were friends from school who knew my Dad from over 25 years ago, Lesley, my dad's wife, kept updating the Caravan & Camping Forum with our progress and a huge amount of money was donated by its members, and

My dad's diagnosis shocked us all, but he is not a man to be easily beaten, he will explore every avenue available (and ones not yet available,) even options that before he would have dismissed ... he is currently exploring Reiki !!!

So Meso watch out!! You don't know what you've taken on with My Dad.

Richard Harris



Richard took part in the Brighton Marathon to diagnosed with mesothelioma, and the Anthony Nolan because his lovely niece Izzy has leukemia.

This is what Richard has to say..."My Dad was diagnosed in January 2012 with Mesothelioma,

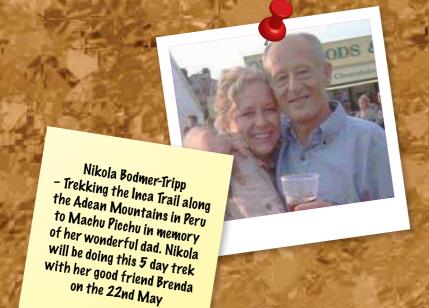
increasing number of people being diagnosed with it and any donations would be greatly appreciated!" Sadly, Dave passed away on the morning of Tuesday 15th January peacefully at home with his family close by.

Richard ran the race on 14th April 2013 supported by his family and friends and this That's amazing, and with gift aid it's actually £2,650.75! ...can we get any more...?

themed evening in aid of Mesothelioma UK. For using her tea rooms as a venue and putting in an incredible amount of time and thought to make raised £2,696.54 for the Anthony Nolan Charity to support Izzy's treatment and on behalf of all of us at Mesothelioma UK I would like to send our very well from your bone marrow transplant. You have one very amazing Uncle Richard!



12 **Mesothelioma Newsletter** - Summer Issue 2013 **Mesothelioma Newsletter** - Summer Issue 2013 13



PSM Consultants -Clare Purser & Stuart Makemson - running the BUPA 10k 27th May

David Barton-Taylor - Took part in the Cambridge Half Marathon in support of Wendy Rule, Pavid's wife's nan who has mesothelioma and he has

raised £754.80

Laura Cheesman - Ran the Hastings Marathon in March in Memory of her lovely dad Andrew and raised £243.75

Per Morton Kind - Took part in the Marathon of the North in memory of her lovely father-in-law Terry Smith and completed the race in 3 hours 12 minutes and 1 second. Per has raised £822.95



Ben Pudmish - Trekking Kilimanjaro Tanzania 13th-16th June

- Race for Life 14th July

Olivia Smallwood

Krysy Pomeroy - Ran the Liverpool Half Marathon in March to get fit and raise money for charity and that she did... she raised £501.25

Andrew Priest - running in the Edinburgh Half Marathon 25th June in support of his Uncle Michael



Chris Willcock taking part in the Blenheim Triathlon on the 8th June 2013

Richard Hollister, Natalie Atentyk & Jane Godfrey - Parachute Jump 6th June

Hazel Pike - Edinburgh Half Marathon 25th June running in memory of her lovely dad, Maurice Macdonald

Laura, Katy & Ron -British 10k London Run 14th July in memory of their friend Denis

Laura Higginbottom, Mat Winterbottom, Pan Hunt, Dave Hunt, Dave Pheasey & Darren Pope -3 Peaks Challenge 22nd June in Memory of Colin Robinson

Sarah Pavies - Running the Midnight Half Marathon in support of her Uncle

Robbie Owen and his niece - running the BTR 10k Mersey Tunnel 9th June

The Trans Pennine Challenge 22nd June 2013

iller, Jennifer Taylor, Sarah Digby White raking on the challenge in support of their lovely Dad Dennis Digby, Stephen Barnes in memory of Peter Bason, Dr Alan Mckenna - supporting the thousands of mesothelioma victims and their familes, and it is about providing greater awareness of this terrible disease. Alice Tipton - In Memory of Nora Tipton.

The BUPA Great Manchester 10k Run 26th May 2013

Wendy Swindells, took part in memory of her lovely mum Mavis, Jonathan Bates in memory of his good friend Michael Street, Natalie Atentyk, Steven Hamble, Denis Higgins & Jason Adshead in memory of Steven Rogers, Natalie's lovely dad.

Mesothelioma Newsletter - Summer Issue 2013 **Mesothelioma Newsletter** - Summer Issue 2013 15

With grateful thanks to our sponsors for 2013

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

To run Mesothelioma UK for 1 year £310,000 is required.

Gold Sponsorship 2013



Silver Sponsorship 2013



Silver Plus Sponsorship 2013



Bronze Plus Sponsorship 2013







Bronze Sponsorship 2013



Event and Service Sponsorships 2013 - Specialist **Nursing Post**



Details of all sponsorship, donations, fundraising and successful grant applications are posted on our website at www.mesothelioma.uk.com