

MESOTHELIOMA UK

National Macmillan Mesothelioma Resource Centre

Patient & Carer Newsletter

Issue 1 – November 2007

2nd MESOTHELIOMA UK Patient and Carer Day

Welcome to Issue 1 of the Patient & Carer Newsletter.

The 2nd Mesothelioma UK Patient and Carer Day held on Saturday 13th October 2007 in London attracted 150 attendees – of these 120 were patients and carers. The feedback has been very positive and Mesothelioma UK hopes to build on this in the future.

I would like to thank Debbie Brewer who has kindly written a report of the day. Much appreciated.

**Best wishes,
Liz Darlison
Consultant Nurse
Mesothelioma UK**

My name is Debbie Brewer. On 13th November 2006 I was diagnosed with Mesothelioma. I was born in 1959 and am the eldest of four daughters. I believe I was exposed to Asbestos through my father's work clothes. My father, Phillip Northmore, worked for the MoD in Plymouth between 1963 and 1966. He was a lagger and would be in close contact with asbestos as his job would mean he would have to scrape asbestos from pipes.



Mesothelioma UK Patient and Carer Day - This is my report of the day.



The picture above is the conference room, which was so professionally laid out. I have never been to a conference before so I was impressed. The speakers were all very informative and there was a lot of very useful information given and most of all, it was very positive.

Continued ...

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Mesothelioma UK, Hospital Management Offices, Glenfield Hospital, Groby Road, Leicester, LE3 9QP

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2nd MESOTHELIOMA UK Patient and Carer Day

There was a welcome from **Helen Clayson** who is the Medical Director at the Hospice of St Mary of Furness in Cumbria.

Mick Peake who is the National Lead Clinician for lung cancer in Leicester, was the first to speak. He talked about Specialist Multi Disciplinary Teams (SMDT). This team would be made up of specialist doctors, surgeons, cancer specialist doctors, specialist nurses, doctors specialising in diagnosis from tissue specimens (histopathologists), physiotherapists, occupational therapists, psychologists, dieticians and any other health professionals. I found out that I can ask who my SMDT is. That will be a question I will take with me. He also said that by 2008 every hospital should have specialist MDTs as Plymouth already as a team as it is a hotspot for Mesothelioma. I did question this as I had gone for a second opinion as I was not satisfied with the information my first Oncologist gave me.

Mick talked about improving services and also said that Mesothelioma had been included in the British Thoracic Society and Dept of health Lung cancer advisory groups. This was changed in Feb 2007. He asked everyone in the room to put pressure on local government where Mesothelioma is concerned.

Jeremy Steele, Consultant in Oncology at St Bartholomew's hospital and chair of Mesothelioma UK explained how cancer created damaged genes. Genes tell your hair to grow and that interested me as I have Alopecia and wondered if that was the reason my hair comes out. He had a lot of very good information.

John Edwards is Consultant Thoracic Surgeon at Northern General Hospital, Sheffield. He urged everyone to write to their primary care trusts and ask for funding for research as a matter of urgency. There is little or no funding for research into Mesothelioma and for trials and treatments. This pressure would hopefully urge the trusts to acknowledge that Mesothelioma is here to stay for the moment and it matters to the people it is affecting.

Helen Clayson talked about minimising the symptoms of Mesothelioma and maximising life. She was also very informative and was a great chair for the event. She kept all the speakers in check by letting them know how long they had left and was very professional.

Tony Whitston is with the greater Manchester Asbestos Victims Support Group and advised the sufferers and their families about their rights with benefits. One benefit few of us knew about was the CONSTANT ATTENDANCE ALLOWANCE. This benefit overlaps DLA and AA and is available to anyone who claims Industrial Injuries Disablement Benefit.

The link below has more information.

<http://www.benefitsnow.co.uk/industrial/constant.asp>

Another benefit is Exceptionally Severe Disablement Benefit which you can get if you receive the CAA benefit above. The link below will detail more information.

<http://www.dwp.gov.uk/advisers/db1/esda.asp>

Carers Allowance is means tested and you will lose it if you earn over £87 week. More info below.

<http://www.carersuk.org/Information/Financialhelp/CarersAllowance>

I also found out that the John Hutton proposal to compensate all Mesothelioma sufferers with IIDB will be brought into force in early 2008. At the moment anyone who has an asbestos related condition cannot get IIDB if they have:

- * Environmental Exposure
- * Self Employment
- * Work/Clothes contamination through third party (family member)

The new rule will hopefully put an end to that rule.

Laurie Kazan-Allen described by Helen Clayson as a "TOXIC RADICAL" as she campaigns to get asbestos banned everywhere and showed some shocking pictures of asbestos factories, schools and wastelands with people standing/working with little or no protection.

One picture showed a manager asking the journalist "what are you worried about" as the manager stood beside his workers in an asbestos filled area. The worst countries are India, Pakistan, Kazakstan, Brazil and the shock one was CANADA. Canada supported the pro asbestos lobby. The link will give more information.

http://www.ibas.btinternet.co.uk/lka_ottawa_conf_rep_03.htm

The first recorded case of Asbestos/Mesothelioma was in 1906.

Graham Sherlock-Brown is a survivor of 5 years and had an EPP (Extra pleural pneumonectomy) which means he had his lung removed. He uses PETAL which is an acronym for:

- P = Positive attitude
- E = Eating and exercising well, (Graham does Pilates)
- T = Targets
- A = Adapting to change
- L = Living your life.

He was very inspirational. Graham presented Mesothelioma UK with a cheque for £5,000 as he had a ball to celebrate his 5th anniversary of survival. He looked very well and it was good to see the positive side of Mesothelioma instead of the negative.

Natalie Doyle, Nurse Consultant Rehabilitation Royal Marsden, London. She talked about the psychological and emotional well being after diagnosis.

She also came out with some very inspirational quotes. "People first cancer second" and "Those who were not here will never know how it is to have survived". She was very helpful with comments and advice, she said that every building has an Asbestos register and anyone could ask to view it.

This was a wonderful, informative day and I learnt a lot more than I anticipated.

I met a lot of wonderful people there. All the people there were so positive and focused. It is a great boost to find we are all striving for the same goal, to survive. I would like to say thanks to my friend Jeannette who was a great support. Also to Rick and Fiona Cooper. Fiona is writing a paper on Mesothelioma and the information carers want/need and what is available. Anyone interested in talking to her can get in touch by emailing: fiona.cooper1@pms.ac.uk

My email address is: phu_phita@hotmail.com

My website: www.Mesothelioma-and-me.co.uk

Written by: Debbie Brewer, Mesothelioma Patient, 14th October 2007

Case studies urgently required: Patients struggling to pay their prescription charges

Macmillan's press and public affairs teams urgently need to hear from cancer patients who are struggling to afford their prescription charges, to provide evidence for their call to the government to make prescriptions free for all cancer patients.

If you are a patient (or know any patients) struggling to pay for their prescriptions and would be willing to help Macmillan in their campaigning work this autumn, please let Macmillan know.

They are campaigning hard to achieve their aim but the key to their success is the ability to demonstrate, through case studies, that charging cancer patients is unfair and unjust.

Please help Macmillan to make sure they can effectively campaign on this issue.

If you can help please contact Julia Anderson, Macmillan Media & PR Officer on 020 7840 7803 or email janderson@macmillan.org.uk.

Opportunity for patients to get involved in Macmillan's cancer and work campaign

Every year in the UK over 100,000 people of working age are diagnosed with cancer. This figure is set to increase as diagnosis and treatment of cancer improve and people work for longer before retirement.

Research has shown that most cancer patients want to return to work. However, a large number find it difficult to manage the side effects of treatment in the workplace and many find that there is a lack of appropriate advice about staying in or returning to work following their diagnosis.

Later this year Macmillan will be launching a campaign focusing on some of the issues faced by cancer patients in work and their employers, as well as highlighting the role Macmillan can play to support them. Macmillan would like to speak to any patients of working age who have had cancer about their experience.

Please contact Katie Austin, Campaigns Officer, on kaustin@macmillan.org.uk or 020 7091 2050.

Parking Costs

Since the publication of *Cancer Costs* in June 2006, over 2,000 people have emailed their elected representative about hospital travel and parking costs. In response, revised guidance has been issued to NHS bodies in England and Scotland. Some hospitals have changed their parking policies, but many more have not. In June 2007 Macmillan asked the public to take further action.

In **England** people can email the chief executive of their local hospital trust to ask how they are following the Government's revised guidance. In **Northern Ireland** people can email the chief executive of the local hospital trust to ask how they are ensuring that cancer patients attending regular treatment do not incur hospital parking charges. In **Wales** people can email the Minister of Health and Social Services to ask how the Welsh Assembly Government will be honouring its election pledge of free parking for radiotherapy and chemotherapy patients and whether this will be extended to all cancer patients attending regularly. Macmillan are also asking what plans there are to issue similar guidance to that which exists in England and Scotland to hospital trusts in Wales. In **Scotland** Macmillan are monitoring the implementation of the revised guidance. Thank you for your help. Please contact Katie Austin, Campaigns Officer, on kaustin@macmillan.org.uk or 020 7091 2050 on what is happening in your hospital in the fight against parking charges.

Mesothelioma Charity Information

Mesothelioma UK is often asked for details of charities that fund Mesothelioma related research. Please find details below:

Mick Knighton Mesothelioma Research Fund

c/o British Lung Foundation
Sir G B Hunter Memorial Hospital The Green
Wallsend
Tyne & Wear
NE28 7PB
Website: www.mickknightonmesorf.org
Email: chrisknighton@mkmrf.freeseve.co.uk
Telephone: 0191 2630276
Payee: Mick Knighton Mesothelioma Research Fund

The June Hancock Mesothelioma Research Fund

c/o Adrian Budgen, Irwin Mitchell
Riverside East
2 Millsands
Sheffield
S3 8DT
Website: www.leeds.ac.uk/meso
Email: adrian.budgen@irwinmitchell.com
Telephone: 0114 2744420
Payee: June Hancock Mesothelioma Research Fund

There is also a **Mesothelioma Research Fund based at St Bartholomew's Hospital, London.**

Website: www.mesothelioma.co.uk Email: jeremy.steele@bartsandthelondon.nhs.uk

Mesothelioma UK currently does not have charitable status but operates financially as an individual cost centre within the University Hospitals of Leicester NHS Trust. Mesothelioma UK is hoping to gain charitable status in 2008.

Currently to donate to Mesothelioma UK, cheques should be made payable to "UHL NHS Trust" and forwarded to Dawn Mckinley, Operational Manager, Mesothelioma UK, Hospital Management Offices, Groby Road, Leicester LE3 9QP. A letter confirming that the donation is for Mesothelioma UK should accompany the donation.

Medical Update

Pemetrexed (Alimta) and NICE

NICE has arranged a hearing for two appeals received against the Final Appraisal Determination and Guidance on this technology.

The appeal hearing will be held at NICE, MidCity Place, 71 High Holborn, London WC1V 6NA, on 23 November 2007 starting at 10.00 am.

Following the outcome of this appeal a Final Appraisal Determination (FAD) will be issued containing NICE's guidance for the use of the drug. Subject to the FAD, Alimta should be widely available in England by Spring/Summer 2008.

Action Mesothelioma Day 27th February 2008

The British Lung Foundation together with asbestos support groups, mesothelioma charities, healthcare professionals and bereaved families who have been affected by the disease joined together in 2006 to form a coalition to campaign on issues that impact people affected by mesothelioma.

The campaign aims to raise awareness of this cancer and calls for faster diagnosis, better treatment and care services, more funding for research and improved measures to prevent future exposure to asbestos. It is important that people are made aware of the possibility of asbestos use in their homes before undertaking DIY or renovation work to ensure that if it is present it is removed safely.

Mesothelioma Charter

The changes and improvements in policy needed in the area of mesothelioma are outlined in the 15 point Mesothelioma Charter which was presented to 10 Downing Street on the first Action Mesothelioma Day (27 February 2006) with more than 14,000 signatures. You can sign the Mesothelioma Charter on the BLF website www.lunguk.org

The British Lung Foundation and the Action Mesothelioma partners are continuing to campaign to achieve the aims set by the 15 point Charter to help prevent future generations being exposed to asbestos and to ensure those affected by this condition have the support and care they need.

If you would like to get involved with Action Mesothelioma Day please contact Mesothelioma UK or check the BLF website www.lunguk.org.

Legal News

In October 2007 the Court of Appeal overturned a ruling that thousands of people diagnosed with pleural plaques should receive compensation.

Insurance companies had appealed against a judgement that pleural plaques, a scarring of the lungs, often resulted in a more serious illness.

Judges said its presence did not mean a person was suffering from any disease and therefore could not make a claim.

The condition has been compensated since the 1980s, Lord Phillips said the court realised the appeal ruling was against 20 years of court practice, but it did not believe this would result in injustice.

The next issue will include ...

- **Patient News and Views**

If you have something you would like to share with other patients or carers please forward to Mesothelioma UK.

- **Macmillan Update**

- **Mesothelioma Charity News**

- **Medical Update**

- **Legal News**

- **Asbestos Support Group News**

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