

MESOTHELIOMA UK

National Macmillan Mesothelioma Resource Centre

Patient & Carer Newsletter

Issue 2 – April 2008

3rd MESOTHELIOMA UK Patient and Carer Day

Welcome to Issue 2 of the Patient & Carer Newsletter.

I am very pleased to announce that Mesothelioma UK will be holding the 3rd Mesothelioma UK Patient and Carer Day in Leeds.

Last year's Day was held in London and the previous year Manchester. Mesothelioma UK does hope to try to hold two patient and carer days per year (North & South) from next year.

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



**Venue: Queens Hotel, Leeds
Date: Saturday 4 October 2008**

The Patient and Carer Day gives Mesothelioma patients, carers and patient relatives the chance to meet and share experiences with others affected by the disease. The Day will also provide up-to-date information on current treatment options, obtaining compensation and benefits and other relevant topics. Mesothelioma patients and carers also have the chance to raise issues and ask questions throughout the Day.

The June Hancock Mesothelioma Research Fund has kindly offered to fund the day. Further details will be available shortly (on the website, forwarded to specialist nurses, asbestos support groups etc).

If you would like to be removed from (or added to) the mailing list, please call the Helpline or complete the details below and forward to:-
Mesothelioma UK, Hospital Management Offices, Glenfield Hospital, Groby Road, Leicester, LE3 9QP

Please X

Remove from mailing list

Add to mailing list

Name:

Address or Email Address:

Helpline: 0800 169 2409

Fax: 0116 2502810

Email: mesothelioma.uk@uhl-tr.nhs.uk

Website: www.mesothelioma.uk.com

Macmillan Website: <http://www.macmillan.org.uk>

Mesothelioma Discussion Forum

The Macmillan Cancer Support **Share** website section includes a discussion forum for anyone affected by Mesothelioma.

Website Link:

<http://share.macmillan.org.uk/share/forums/?tag=mesothelioma>

Cancer Information Centres

The Macmillan Cancer Support website includes a section where you can search for Information Centres in your area. The centres can offer benefits advice, complementary therapies, counselling and information.

Website Link:

http://www.macmillan.org.uk/Get_Support/Find_information/Find_cancer_information_centres.aspx

Starting a Support Group

You can also access useful information regarding self help and support groups including guidelines for setting up a cancer self help or support groups on the Macmillan Cancer Support website.

Website Link:

http://www.macmillan.org.uk/Get_Support/Cancer_support_groups/Resources.aspx

YouthLine

If you know someone between 12 and 21 years old and someone close to them has Mesothelioma and they need to talk they can call the **Macmillan YouthLine on 0808 808 0800**



Monday - Friday 9am - 9pm

Macmillan Cancer Support says we know the impact cancer can have. We are used to talking about it and we're good at listening. It's free, confidential and it won't show up on the phone bill.

Email youthline@macmillan.org.uk

Action Mesothelioma Day 27th February 2008

The main aim of Action Mesothelioma Day 2008 was to build on previous years with regard to raising awareness of mesothelioma and campaigning on the points in the Mesothelioma Patient Charter.

The British Lung Foundation launched a media campaign to raise awareness of the dangers of asbestos and held a parliamentary reception at the House of Commons. Unfortunately, the news media was mainly dominated by news of the earthquake that was felt by England in the early hours of the 27th.

However, the day did see some very successful events being held around the country. These events were poignant, moving and campaigning and Mesothelioma UK would like to applaud those who participated, organised or attended an event in support of Action Mesothelioma Day 2008.

Leicester

Leicester saw the third event organised by Linda Thornton, whose husband, Roger died with Mesothelioma. Balloons were released in a multi-faith service at Leicester Town Hall Square in honour of victims.



Birmingham

At St Philips Cathedral Birmingham doves were released in memory of Mesothelioma sufferers.



Merseyside & Cheshire

Members and supporters of the Merseyside and Cheshire Asbestos Victims Support Groups held a meeting and balloon release at Liverpool Town Hall to raise awareness of Mesothelioma and how its legacy has affected thousands of people on Merseyside and Cheshire. Children from Holy Cross Primary School, Liverpool attended as representatives of future generations.



Civic Dignitaries from all over Merseyside and Cheshire including the Deputy Lord Mayor of Liverpool and the Mayor and Mayoress of Halton, (Cheshire) attended the meeting to hear a number of speakers including Dr. Chris Warburton, Consultant Chest Physician.

South Yorkshire

Sheffield and Rotherham Asbestos Group held a balloon release in Doncaster and planted camellia shrubs in Weston Park, Western Bank, Sheffield in memory of Mesothelioma sufferers.



Manchester

In Manchester 130 people attended a sponsored balloon release and public meeting in Albert Square.



Portsmouth

Hampshire Asbestos Support & Awareness Group's first Action Mesothelioma Day event was marked by a balloon release & meeting at Portsmouth Guildhall. Speakers included Dr Mark Roland, Consultant Respiratory Physician, Laurie Kazan-Allen and Megan Dobney of SERTUC.



East London

ELMS (East London Mesothelioma Support) held the very first event in East London. The event was organised by Eileen Beadle of ELMS whose husband Ray died from Mesothelioma. The event took the form of a fundraising coffee morning at Newham Town Hall and a sponsored Balloon Release. The Mayor of Newham, Mayor of Waltham Forest, Newham's Civic Ambassador and local councillors were in attendance. A prayer was said by Father Tom Duncan followed by a one-minute silence in memory of all victims of Mesothelioma.



Tyne & Wear

An information day to raise awareness about an asbestos related disease was attended by more than 100 delegates in the North East. The event, held by the Mick Knighton Mesothelioma Research Fund at Gateshead Civic Centre, provided a one-stop shop to people from all backgrounds about the disease.



Speakers included Dr Jeremy Steele, Consultant in Oncology at St Barts and Chair of Mesothelioma UK, Dr Albi Ryan Recipient of the MKMRF Award 2006, Ian McFall Head of the Asbestos Litigation Team at Thompsons Solicitors and Rob Hirst Inspector for Health and Safety Executive. The event was Chaired by Dr Tim Peel, Lead Clinician for Northumbria in Lung Disease and Palliative Care.

Legal News

“Trigger Issue” Litigation

Written by: **Adrian Budgen and Helen Ashton, Lawyers**

The High Court in London will be asked to decide this summer* whether certain insurance companies should pay out compensation in a group of Mesothelioma cases. They will look at a number of insurance policies and the words used in them to decide whether the insurers should be responsible when someone is exposed to asbestos or when the mesothelioma develops.

When someone suffers an injury at work, for example as a result of a fall, it is easy to identify when it happened and who was responsible. In a mesothelioma case, where the illness may not show itself until many years after exposure to asbestos, it is not so easy to identify exactly when it happened. Employers typically have two sorts of insurance: an employer’s liability insurance policy which protects them against claims for injuries or illnesses suffered by their employees; and a public liability insurance policy, which they take out to insure them against claims from people other than employees.

In a recent appeal court case, a judge had to decide when an injury in a mesothelioma claim had “occurred” under a public liability insurance policy, the word “occurred” being the trigger for the policy to respond. The Court decided that the injury had not occurred at the time of the exposure, but that it had occurred when the tumour began. It was following this decision that a number of insurance companies, who are now in liquidation, denied that the employer liability insurance policies they supplied to companies which provided cover for injuries “sustained” or diseases “contracted” during the policy, covered mesothelioma claims. They are arguing that an injury is only “sustained” or a disease is only “contracted” when the tumour emerges.

If it is decided that the injury / illness in a mesothelioma claim was not sustained, or contracted, during the period of insurance, then there is no obligation on the insurance company to pay out. In many cases, where the employer is no longer in business, this could mean that the mesothelioma sufferer would not receive any compensation. We, along with other lawyers and campaigners, are now fighting to ensure that the implications of any decision in favour of these insurance companies is known and we are determined to highlight the injustice such a result would mean for mesothelioma sufferers.

* The trial of this issue is due to commence on 3rd June 2008 and is listed for 9 weeks. Judgment is likely to be reserved which means a decision will be made 2-3 months after the hearing.

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.freeserve.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.junehancockfund.org.uk
Email: info@junehancockfund.org
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 Summer 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.

Charity News

June Hancock Mesothelioma Research Fund

Written by: Kimberley Stubbs

A very successful public event was held by The June Hancock Mesothelioma Research Fund (JHMRF) at the Civic Hall in Leeds, in conjunction with RASAG (Ridings Asbestos Support and Awareness Group) based in the mesothelioma hotspot of Armley, Leeds.

More than 50 people attended; a mixture of patients, carers, bereaved families and those with an interest in finding out more about asbestos disease and what they can do to help.

We had a number of terrific speakers on the day – Russell Hancock son of June Hancock opened the event with a moving account of how mesothelioma first became known to him when Steve McQueen died of it in 1980. How little did he know, that it would also take the life far too soon of his grandmother, Maie Gelder in 1982, and his mother, June Hancock in 1997. Many in the audience were moved to tears. Patients Dave Nicholls and Pauline Cade then spoke candidly about their experience of mesothelioma, and how determined they are to live life to the full. That they gave their time so freely and spoke so honestly is testament to their strength of character. Ann Lee, a volunteer at RASAG who lost her husband to mesothelioma also talked about her experiences, and how she is now helping others.

Alice Nutter is a Yorkshire Playwright responsible for the recently aired “Snow in July” on Radio 4. She spoke about what drove her to write this play, and how well it was received. She plans to do more to highlight the plight of people exposed to asbestos in the past, present and future. Speaker Ken Yates is also a Yorkshire playwright who is hoping to commission a play based on the Armley asbestos tragedy, and June Hancock’s legal battle with T&N. He has been researching this for many years. He brought with him a number of actors to play out an excerpt of the play “Dust” which was very well received by everyone, and added a highly unusual element to the day’s events.

David Snowball (Health & Safety Executive Yorkshire) then spoke about the recent campaign, and how it had evolved over the years. David is also the Regional Director of the HSE Asbestos Campaign. Rory O’Neill is a well respected international health & safety researcher, campaigner, and Editor of ‘Hazards’ magazine. He spoke at length about his determination to keep the travesty of the asbestos legacy high on both the political and public agenda.

Finally, John White, a Macmillan Nurse Specialist spoke about the National Service Framework for Mesothelioma. A question and answer session at the end was the perfect opportunity for everyone to be involved.

New Charity Status and Other News

2007 is an important landmark in the JHMRF’s history. The JHMRF has formally relaunched as an independent Charity in December 2007 – Charity Number 121784. The Trustees are delighted and held a Christmas buffet to celebrate this, in memory and honour of June Hancock. It was also 10 years since the Fund was launched. The 19th July 2007 marked the 10th anniversary of June’s death from mesothelioma.

The JHMRF are also pleased to announce that we have joined as an Associate Member. We are looking forward to working closely with others to improve the plight of asbestos disease patients and their carers.

We are delighted to have a new and updated version of the extremely helpful ‘[Mesothelioma – A Patients Guide](#)’ available. This is available in both hard copy (from the address below or RASAG) or downloadable from the June Hancock Mesothelioma Research Fund website. This guide, written by Mavis Robinson MBE, has proved invaluable over the years and is free to patients and their carers. Many have benefited from the clear, concise, quality and up to date information contained within it.

Medical Update

Pemetrexed (also known as Alimta) for Malignant Pleural Mesothelioma Extract from “Understanding NICE Guidance – Information for people who use NHS services”

The NICE (National Institute of Clinical Excellence) Technology Appraisal was issued on 23rd January 2008. Pemetrexed is recommended as a possible treatment for malignant pleural mesothelioma in people with advanced disease, whose cancer is not suitable for surgical resection (removal) and who have a World Health Organisation (WHO) performance status of 0 (able to carry out normal activity without restriction) or 1 (restricted in strenuous activity but able to move around and carry out light work).

When NICE recommends a treatment, the NHS must ensure it is available to those people it could help, normally within 3 months of the guidance being issued. If you have advanced malignant pleural mesothelioma which is not suitable for resection (removal), a WHO performance status of 0 or 1, and your specialist thinks that pemetrexed is the right treatment for you, you should be able to have the treatment on the NHS. If you are already taking pemetrexed for malignant pleural mesothelioma, you should be able to continue taking it until you and your specialist decided it is the right time to stop.

Chemotherapy In Mesothelioma Project – ChIMP

Mesothelioma UK is leading ChIMP (**C**hemotherapy **I**n **M**esothelioma **P**roject). It is a 1 year national project that launched on 1st February 2008.

The project aims to clarify what, where and how much chemotherapy treatment is being prescribed to mesothelioma patients in England.

Once completed the audit will help the funders of healthcare assess the likely cost impact, provide evidence relating to the patient group being treated, where patients are being treated and give important insight to improve patient access to chemotherapy (when suitable).

Mesothelioma UK would respectfully ask that Mesothelioma patients receiving chemotherapy should urge their oncologist or specialist nurse to register and participate in this project.

ChIMP information can be accessed through the Mesothelioma UK Helpline (0800 169 2409) or on the website, www.mesothelioma.uk.com.

The next issue will include ...

- **Patient & Carer News**
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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