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**MESOTHELIOMA UK**  
National Macmillan Mesothelioma Resource Centre

## **Bulletin January 2008**

### **MESOTHELIOMA UK UPDATE**

The helpline continues to be open Monday – Friday 09.00 -16.30 hours. To date it has taken 2030 calls, averaging 73 a month or 17 calls per week. We have also received 435 email enquiries. The website is continually being reviewed and currently receives over 1000 hits each month.

In October 2007 Mesothelioma UK held the second patient and carer day in London. An overwhelming 150 delegates attended and evaluation following the event was outstanding. A Mesothelioma UK Newsletter for patients and carers that will be distributed quarterly was launched shortly after, which included a comprehensive write up by Debbie Brewer on the Patient and Carer day presentations. For more information please check the Mesothelioma UK website.

The third Mesothelioma UK Symposium at the National Lung Cancer Forum for Nurses annual conference was also held in November 2007 and again this received excellent evaluation.

Working with the Asbestos Diseases Forum a booklet advising mesothelioma patients how to gain access to Pemetrexed has recently been completed. It explains the NICE process for approving drugs, how to apply for funding and appeal against local negative PCT decisions. Copies can be obtained from any of the Asbestos Diseases Support Groups or Mesothelioma UK.

Having secured funding for the next 18 months Mesothelioma UK has entered a second stage of development. Priorities for stage 2 include:-

- Securing long term funds and applying for charitable status
- Supporting the implementation of the National Mesothelioma Framework.
- Developing the Network Mesothelioma Lead Nurse Group
- Increasing Mesothelioma UK patient and carer events
- Developing National Mesothelioma Information Pathway
- Providing a web based interactive forum for patients and carers
- Completing a national mesothelioma chemotherapy audit

### **Mesothelioma Nurse Action Team M-NAT**

In response to the National Mesothelioma Framework 30+ members of the National Lung Cancer Forum for Nurses, representing every cancer network, have joined forces to form an action team, M-NAT, the aim being to identify priorities for nurses within mesothelioma care and develop a national action plan to enable nurses to work together to achieve improved standards. The team's progress will be reported in the Mesothelioma UK bulletin.



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# ACTION MESOTHELIOMA DAY – 27<sup>th</sup> FEBRUARY 2008



The third annual Action Mesothelioma Day (AMD) is being held on February 27<sup>th</sup> 2008. The main aim of AMD will be to build on previous years with regard to raising awareness of mesothelioma and campaigning on the points in the Mesothelioma Charter. A variety of activities are taking place around the UK, many organised by Asbestos Support Groups, patients and carers. The British Lung Foundation has surveyed cancer networks to evaluate progress made toward the National Mesothelioma Framework. They are also continuing to explore the variation in coroners' practice and will be holding a parliamentary reception.

Mesothelioma UK communicates events for the day to everyone and anyone interested. If you are organising an AMD event in your area please forward details so that we can let everyone know.

## **Action Mesothelioma Day Case Studies**

The BLF are hoping to get The Sun to support this year's Action Mesothelioma campaign and the health editor seems quite keen as trades people are among their key readers, but would ideally like three case studies, so for example, a builder, carpenter and gas fitter.

If you have a patient who would consider having their story 'in print' please seek their permission and forward their details to Mesothelioma UK or to Kerry Kalcher, Press Officer, The British Lung Foundation, Tel: 0207 688 5564.

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## **Pleural Plaques Ruling**

In October 2007 the Law Lords ruled pleural plaques is not a disease. For people diagnosed with Pleural Plaques the decision removes an established right to compensation which has existed for 20 years. The Lords accepted that employers had been negligent but denied workers the right to any form of redress.

## **Mesothelioma Provisions in the Child Maintenance and Other Payments Bill (CMOP)**

Little has changed since we last reported on this bill in July 2007 and until it is enacted regulations remain unchanged. If you would like to keep up with what is happening yourself follow the link Bills and Legislation under the Business Heading <http://www.parliament.uk/>

Meso UK was contacted recently by one department within the DWP. Forms are currently being developed for the new act which is currently referred to as the 2008 Diffuse Mesothelioma Act. It is thought that the act will be in place by this summer.

## **Health Technology Appraisal** **Pemetrexed disodium for the treatment of mesothelioma**

Nice have now confirmed that full guidance along with the final appraisal decision will be published and made available on their website ([www.nice.org.uk](http://www.nice.org.uk)) on Wednesday 23 January 2008.



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## **British Mesothelioma Interest Group**

The BMIG held its first meeting in Leicester in 2001, when 183 delegates met to discuss research findings and clinical aspects of mesothelioma. This meeting was highly successful and attracted the regional press and television. All went quiet for a while, whilst BMIG was incorporated into the ever-growing British Thoracic Oncology Group, which has held annual meetings since 2003. A BMIG Investigators Meeting was held in July 2007 in London, at which point it was decided to use the organisation to:

- disseminate information about basic science research
- encourage collaboration between research groups
- act as lobby group for matters pertaining to mesothelioma research, in particular to dedicated research funding
- act as a “think tank” for future clinical trials, reporting to the National Cancer Research Network Mesothelioma Subgroup

Co-ordinated by Mr John Edwards, Consultant Thoracic Surgeon in Sheffield, the BMIG intends to meet twice yearly with these aims in mind. There will be two sessions dedicated to Mesothelioma at the BTOG meeting at the end of January, at which basic science research and current and future trials of chemotherapy and surgery will be discussed.

Mr Edwards can be contacted at [john.edwards@sth.nhs.uk](mailto:john.edwards@sth.nhs.uk)

## **Royal Oldham Hospital Cordotomy Service**

The Department of Health early this year produced their Mesothelioma Framework document. In this it stated that palliative care plays a key role in these patients care. To quote:

“Specialist palliative care including specific interventions such as radiotherapy to the site of chest drainage/biopsy, nerve blocks & cordotomy, are of particular importance in providing relief for some patients”.

Cordotomy is a specialised pain intervention technique, which can be done under local anaesthetic. It is best done early if indicated, rather than late in the disease when patients are unable to lie flat for the procedure. Doing large numbers in a specialist centre is more likely to consistently achieve high success rates with low complication rates. Currently the only centre doing large numbers of patients each year in the UK is at Portsmouth.

In order to provide cordotomy services across the country a large expansion will be required, to allow sufficient numbers to meet demand and to allow for convenient patient access to these specialist services.

A new service outside Manchester has been established in the Royal Oldham Hospital by myself and is open for referrals from December 2007.

I am attempting to contact known cordotomy practitioners across the UK to try to encourage the establishment of a service within each Strategic Health Authorities (SHAs). To date Dr Hugh Antrobus (see previous newsletter) has agreed to coordinate a cluster of clinicians around Birmingham area.

Each new ‘centre’ will need a small core of doctors who are prepared to do large numbers of cases (at least 40-80 per annum) with the resource implications implied on time and funding. This will ensure service continuity. They will need Trust and regional backing. In addition, training new additional practitioners will be a priority. For more information contact: Dr Paul Cook, Consultant in Anaesthesia & Palliative Care on: 0161 627 8829 or email: [paul.cook@pat.nhs.uk](mailto:paul.cook@pat.nhs.uk).



## **TRIALS UPDATE**

### **MALCS and TIPS**

MALCS was set up over 6 years ago, to recruit mesothelioma and primary resected lung cancer patients from across the UK, and we have obtained MREC approval to continue recruiting patients until 2015.

We aim to identify the occupations and work practices currently conferring the highest risk of mesothelioma through telephone interviews with patients.

We would like to say a big THANK YOU to all those individuals and centres who have been recruiting patients for us over the years and encourage you to continue. We would also be delighted to hear from new centres able to recruit patients for us. We are actively seeking to recruit all female mesothelioma patients (of any age) and male mesothelioma patients aged under 60. In addition, we are seeking to recruit male resected lung cancer patients born after 1940. Data from the first 624 mesothelioma patients and 425 resected lung cancer patients interviewed and are just about to be published and anyone on our mailing list will receive an outline of these results.

The Inhaled Particles Study (TIPS) is closed to recruitment of new centres as we have enough centres currently participating.

TIPS was set up to evaluate the risk of mesothelioma to much younger (construction and other) workers. This study will also determine any possible risks from current environmental or DIY asbestos exposures.

If you would like to help us with MALCS and you see mesothelioma patients or resected lung cancer patients, we would be delighted to hear from you.

Please contact the MALCS study team on [MALCS@icr.ac.uk](mailto:MALCS@icr.ac.uk) or email [Elaine.Mills@icr.ac.uk](mailto:Elaine.Mills@icr.ac.uk).

### **MESO VATS Trial**

The MesoVATS study has seen a marked increase in activity at Papworth towards the end of last year and we predict that this trend is likely to continue for a while as we have several patients in screening at the moment. Recruitment at Guys and Leicester is ongoing although numbers are small. It is hoped that Basildon (Andy Ritchie), Brompton (Eric Lim) and Sheffield (John Edwards) will all soon be in a position to start recruiting - all systems are in place to facilitate this. We are optimistic that with six surgical centres and their local hospitals, we will experience a corresponding rise in MesoVATS activity. For further information, please contact either Helen Munday - [helen.munday@papworth.nhs.uk](mailto:helen.munday@papworth.nhs.uk) or Robert Rintoul - [robert.rintoul@papworth.nhs.uk](mailto:robert.rintoul@papworth.nhs.uk).

## **Chemotherapy in Mesothelioma Project (ChIMP)**

**ChIMP (Chemotherapy In Mesothelioma Project)** is a 1 year national project that 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 health care assess the likely cost impact, provide evidence of the characteristics of the patient group being treated, their fitness for treatment and any toxicity they experience. It should demonstrate where such patients are being treated and give insight into the frequency of suitable patients not being treated and why this occurs.

A clinical advisory group is monitoring progress of the audit and every effort has been made to ensure the audit is patient focused, uncomplicated and remains as user friendly as possible. Any help and support required by clinical teams to enter patients into the audit will be provided where possible.

Our intention is to start the audit on the 1<sup>st</sup> February 2008 and get as many centres involved as possible. We will be attending BTOG where you will be able to enrol your hospital or centre on the day or pick up an information leaflet.

Mesothelioma UK is leading this project and with your help and support it will be a success. For further information contact Jill Lemon via Mesothelioma UK Mon - Fri 9.00am – 5.00pm on 0800 169 2409 or e-mail [mesothelioma.uk@uhl-tr.nhs.uk](mailto:mesothelioma.uk@uhl-tr.nhs.uk)

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## **FORTHCOMING EVENTS**

**9th European Congress: Perspectives in Lung Cancer – 14<sup>th</sup> – 15<sup>th</sup> March 2008**  
Venue: Torino, Italy

Website: [www.uicc.org](http://www.uicc.org)

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**Post Graduate Course in Lung Cancer – 17<sup>th</sup> – 18<sup>th</sup> March 2008**  
Venue: Clinical Education Centre, Glenfield Hospital, Leicester

Website: [www.ilh.org.uk](http://www.ilh.org.uk)

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**1<sup>st</sup> European Lung Cancer Conference – 23<sup>rd</sup> – 26<sup>th</sup> April 2008**  
Venue: Geneva, Switzerland

Website: [www.uicc.org](http://www.uicc.org)

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**Lung Cancer and Mesothelioma Facing the Challenge! – 13<sup>th</sup> May 2008**

Venue: Kent & Medway NHS Trust

David Salomans House, Broomhill Road, Southborough, Royal Tunbridge Wells

Contact Frances McKay on 01634 825212 or Caroline Williams on 01634 825391

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**International Lung Cancer Conference, Liverpool – 9<sup>th</sup> – 12<sup>th</sup> July 2008**

Venue: Arena & Convention Centre, Liverpool

Website: [www.ilccl2008.com](http://www.ilccl2008.com)

If you have any news you would like included in the next Bulletin, please forward it to Mesothelioma UK.

Yours faithfully

*Liz Darlison*

Liz Darlison  
Mesothelioma UK



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