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**MESOTHELIOMA UK**  
National Macmillan Mesothelioma Resource Centre

## **Bulletin October 2008**

### **MESOTHELIOMA UK UPDATE**

Mesothelioma UK Charitable Trust is now successfully registered with the Charities Commission. Once a bank account has been set up in the charity's name donations can be received. Further details will be posted on our website. The charity exists to raise money to fund the services provided by Mesothelioma UK; namely the helpline, website, educational events, newsletters etc. In the last quarter Mesothelioma UK has received 231 contacts via the helpline or email and there have been 1669 hits on the website.

The Mesothelioma Nurse Action Team (M-NAT) met again and progress toward the provision of a National Mesothelioma Information Pack continues. M-NAT has also submitted a research grant application to look at patient, carer and healthcare professionals' information and education needs. The outcome of this submission will not be known until early 2009.

The 3<sup>rd</sup> Mesothelioma UK Patient and Carer Day, sponsored by the June Hancock Mesothelioma Research Fund, was held on Saturday 4<sup>th</sup> October at the Queens Hotel in Leeds. The day has been extremely well evaluated by the 144 delegates. A big thank you to nurses Gerry Slade, Maria Guerin, Sally Moore and June Morley for coming along to be on hand if patients and carers needed any one to one advice or support. Also thank you to Dr Helen Clayson for her excellent chairing skills and to the following speakers for giving up their Saturday and generally for their commitment to this annual event:-

Gerry Coombs  
Natalie Doyle  
Jill Morrell  
John Edwards  
Jeremy Steele  
Anthony Whitston  
David Garrod  
Debbie Brewer

Discussions are underway about Action Mesothelioma Day 2009 and our first newsletter highlighting various activities to mark the day will be circulated during November.

Finally, there are now Mesothelioma CNS posts in Cambridge, Oxford, Kent and Medway, Leicester and Guy's and St Thomas's. Anyone looking to develop a similar post should contact Mesothelioma UK to be put in contact with existing post holders.



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# **ChiMP – Chemotherapy in Mesothelioma Project**

“HAVE YOU REGISTERED WITH ChiMP?”

We are open and keen to accept your registration, you can send for your ChiMP starter pack today by e-mailing [mesothelioma.uk@uhl-tr.nhs.uk](mailto:mesothelioma.uk@uhl-tr.nhs.uk)

Since the ChiMP project was launched back in February we are now finding that a few sites who have registered with the ChiMP project although full of enthusiasm and raring to go have been finding it difficult to sort out who in what areas would be able to collate the data and register patients for the project. The problem seems to be that some of the chemotherapy centres cover large areas and as always, the staff are very busy with time constraints, holidays, sickness etc. We had envisaged that this may be a problem to some and we are currently trying and hoping to get across to all concerned how simple this project is and how we can help make it easier for you to register your patients. You will perhaps find it easier to register your patients retrospectively perhaps once a month or when you have an amount of patients who have finished their treatment regimes.

You initially may need help to get you started by registering the back log of patients that has accumulated since February, I am willing to help there, by perhaps arranging a visit to your site and with your help start to get this task underway so that future registrations are easier. We are available to help you with your enquiries by e-mail or telephone so please contact us, ‘don’t struggle’.

On a positive note, you have increased our patient registration to 315 and being in our 7<sup>th</sup> month this is a fantastic achievement, so ‘please’ keep up the good work. I hope this information helps to both encourage those sites already registering patients and for those who are about to join us.

We hope you will support this worthwhile project and look forward to you joining us.

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## **TRIALS UPDATE**

### **MARS**

103 patients have now been recruited to the registration phase of MARS. Of these, 42 patients have now been randomised. Thank you to everyone who has helped to achieve this. For more information about the MARS trial email: [mars-icrctsu@icr.ac.uk](mailto:mars-icrctsu@icr.ac.uk)

### **MALCS/TIPS**

The Inhaled Particles Study (TIPS) now has 3 active centres (Guys, Royal Brompton and Birmingham Heartlands) and is open for recruitment at other centres. The aim of TIPS is to assess potential mesothelioma risk in current construction workers, by recruiting pneumothorax patients who have undergone an operation and had a small piece of tissue removed.

Consenting pneumothorax patients would be interviewed and the asbestos fibre content of this lung tissue evaluated. In combination with the results of our Mesothelioma and Lung Cancer Study (MALCS), the risk to current construction industry workers could then be assessed. If you are interested in TIPS and your centre see's appreciable numbers of pneumothorax

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patients, please contact the TIPS study team (c/o Christine Rake) on 020 8722 4298, or e-mail [TIPS@icr.ac.uk](mailto:TIPS@icr.ac.uk)

Recruitment for MALCS (Mesothelioma and Lung Cancer Study) is ongoing until 2015. Recruitment is slow and NCRN points are available for the study - so please help us if you can! We are seeking to recruit MALE MESOTHELIOMA and RESECTED LUNG CANCER PATIENTS born after 1940, and FEMALE MESOTHELIOMA PATIENTS born after 1925 (no female lung cancer patients). We are evaluating potential ongoing risks to these target groups and would value new contacts for study recruitment.

We would like to express our continuing gratitude to all patients who are involved with our research. It is only with the help of patients, that we may be able to understand more about the disease and its epidemiology. We would also like to thank all those involved in recruitment to the study, and to encourage you to continue, as your help is invaluable to us.

If you are not currently recruiting, or if you want to check if someone at your centre is already recruiting for MALCS, please contact the MALCS study team (c/o Christine Rake) on 020 8722 4298, or e-mail [MALCS@icr.ac.uk](mailto:MALCS@icr.ac.uk)

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### **Pleural Plaques**

The following link: <http://www.justice.gov.uk/docs/cp1408.pdf> is a copy of the pleural plaques consultation issued on 9 July 2008 with a list of questions for response: <http://www.justice.gov.uk/docs/cp1408-questions.doc>. The Association of Personal Injury lawyers will be responding. If you have any comments you would like to be considered for inclusion in APIL's response please contact [abi.jennings@apil.org.uk](mailto:abi.jennings@apil.org.uk).

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### **Coroners and Death Certification Bill**

When someone dies from mesothelioma, an asbestos related cancer, it is classified as 'an unnatural death' and a coroner must carry out an inquiry.

As was highlighted in the British Lung Foundation report 'An Unnatural Death', when a death from mesothelioma occurs outside of a coroner's working hours the bereaved can be visited by uniformed police in a marked police car, sometimes in the middle of the night. Many relatives say that this leads them to feel under suspicion during a distressing time.

We welcome the inclusion of the Coroners and Death Certification Bill in the Draft Legislative Programme for 2008-09 and the publication of the updated Charter for the Bereaved, which states that a Chief Coroner should be appointed and set minimum service standards for mesothelioma inquiries.

We urge the Prime Minister to ensure that the Bill is passed in the next parliamentary session and that coroner's inquiries are consistently sensitive to the needs of families bereaved by mesothelioma. To sign the BLF's petition please go to link below.

<http://petitions.number10.gov.uk/meso-inquiries/>



## Diffuse Mesothelioma - New Payment

On 1 October 2008, a new Government scheme will be introduced for people suffering from the asbestos-related disease, diffuse mesothelioma.

If a person is unable to make a claim under the 1979 Pneumoconiosis Act, has not received payment in respect of the disease from an employer, a civil claim or elsewhere and is not entitled to compensation from a Ministry of Defence Scheme, they can claim a one-off lump sum payment.

The scheme covers people whose exposure to asbestos was not as a result of their work as an employee, for example:

- they came into contact with asbestos from a relative (for example, by washing their clothes)
- they were exposed to asbestos in the environment (for example, they lived near a factory using asbestos)
- their exposure to asbestos was while self-employed, or
- their exposure cannot be specified but it occurred in the United Kingdom.

Claims should be made as soon as possible after 1 October 2008 using form PWC1. There will be no time limits for claims from sufferers made during the first year of the scheme but after that time, claims must be received within 12 months of the date of diagnosis.

The aim is to make the payment within six weeks of receiving the claim form.

People will be asked to submit medical evidence with their claim showing that they are suffering from diffuse mesothelioma caused by exposure to asbestos. A further medical examination will not be required.

If the sufferer has died, their dependants may be able to claim. The claim form must be received within 12 months of the date of death.

### Further information

Customers should telephone Barrow Industrial Injuries Benefit Delivery Centre on **0800 279 2322** for further information and to request a claim form.

## **Mesothelioma & Asbestos Awareness Center Hails Effects Of Breakthrough Drug Combination For Elderly Pleural Mesothelioma Patients**

Alimta and Paraplatin combination found to be especially successful in older mesothelioma sufferers

An Italian study involving the effectiveness of Alimta (pemetrexed) and Paraplatin (carboplatin) was revealed at the 12th World Conference on Lung Cancer in 2007 and recently published in the British Journal of Cancer in June of this year. The study states that this combination of drugs is highly effective in [pleural mesothelioma](#) patients aged 65 or older.

Pleural mesothelioma is a fatal type of cancer affecting the pleural lining of the lungs. It is conclusively caused by prior exposure to asbestos. Pleural mesothelioma has a latent period of between twenty and fifty years, and the majority of individuals who receive a mesothelioma diagnosis are between the ages of 50 and 70 years old. The survival rate associated with pleural mesothelioma is less than one percent, and most mesothelioma sufferers will unfortunately surrender to this aggressive form of cancer in less than two years following their initial diagnosis.

The Alimta and Paraplatin duo has a one-year survival rate of over 60% and is very effective in older mesothelioma patients, with a median survival rate at about 14 months for individuals in the older age group (age 70 or older) as opposed to a survival rate of 11 months in participants in the younger age group.

There is presently no known cure for pleural mesothelioma. However, various [mesothelioma treatment](#) methods, including chemotherapy and other drug combinations, may control the disease and lessen the presence of mesothelioma symptoms in patients.

The Mesothelioma & Asbestos Awareness Center acknowledges the combination of Alimta and Paraplatin as an effective method of mesothelioma treatment and expresses the ongoing urgency for increased funding for mesothelioma-related studies and research.

The Mesothelioma & Asbestos Awareness Center is the web's leading resource for information related to asbestos exposure, mesothelioma, mesothelioma treatment, top doctors, and more. For additional information, please visit the Mesothelioma & Asbestos Awareness Center at <http://www.maacenter.org/>.



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## You are more at risk than you think – Asbestos: The hidden killer

It is hard to believe that every week 20 tradesmen, including plumbers, joiners and electricians, die from asbestos related diseases caused simply by breathing in asbestos fibres. Asbestos-related disease is the biggest single cause of work-related deaths, and accounts for around 4000 deaths per year.

The Health and Safety Executive is launching its campaign '**Asbestos: The hidden killer**' on 13 October 2008, which is aimed at making tradesmen aware of asbestos and the damage it can cause to their health and lives

- More people die from asbestos-related disease per year than are killed on the roads
- Every week 20 tradesmen die from asbestos-related disease
- Every week 6 electricians die from asbestos-related disease
- Every week 6 joiners die from asbestos-related disease
- Every week 3 plumbers die from asbestos-related disease
- It can be present in any building built or refurbished before the year 2000
- The issue of asbestos has not gone with our forefathers - risks with asbestos still exist
- You may not realise it but you may be disturbing asbestos when you work
- Even today around 500,000 non-domestic buildings contain asbestos
- Generally, asbestos is only a risk if it is disturbed or damaged so that fibres are released into the air. If asbestos containing materials are in good condition and in a position where they are not going to be disturbed or damaged then it is safer to leave them where they are and ensure that the risks are managed
- The Control of Asbestos Regulations [2006] require mandatory information, instruction and training for anyone liable to be exposed to asbestos fibres at work

### Don't work if:

- You're unsure whether asbestos is present – your employer or the customer should tell you;
- Asbestos is present but you have not been trained to work safely with it;
- The asbestos materials present are sprayed coatings, board or lagging on pipes and boilers – only a contractor with a licence should work on these.

### Only work with asbestos if:

- You have had asbestos training, the work is properly planned and the right controls are in place (e.g. you have the right equipment);
- The materials are asbestos cement, textured coatings containing asbestos or others which do not need a licence.

## Campaign

- A national campaign is being launched on October 13<sup>th</sup> 2008, to raise awareness among tradesmen [esp. electricians, plumbers and joiners] that the risk of asbestos is relevant to them and can damage their health
- The campaign will run for 6 weeks
- Adverts will feature on the radio, in newspapers and trade magazines
- The new packs have additional information and advice on training

## Further information

- HSE's asbestos web pages at [www.hse.gov.uk/hiddenkiller](http://www.hse.gov.uk/hiddenkiller)
- *Asbestos essentials* gives guidance on non-licensed work – download it from the asbestos web pages at [www.hse.gov.uk/asbestos](http://www.hse.gov.uk/asbestos)
- *Protect yourself against the hidden killer: Work safely if asbestos is present* HSE campaign leaflet, available at [www.hse.gov.uk/hiddenkiller](http://www.hse.gov.uk/hiddenkiller)
- Full details of the Control of Asbestos Regulations 2006 are available on [www.hse.gov.uk/asbestos/regulations.htm](http://www.hse.gov.uk/asbestos/regulations.htm)
- HSE's Infoline Tel: 0845 345 0055 Textphone: 0845 408 9577 e-mail: [hse.infoline@natbrit.com](mailto:hse.infoline@natbrit.com)

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## Forthcoming Events

### **Management of Clinical N2 Disease in Early NSCLC 27<sup>th</sup> October 2008**

Venue: Royal Brompton Hotel, London

Website: [www.thoracics.co.uk](http://www.thoracics.co.uk)

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### **10<sup>th</sup> Annual National Lung Cancer Forum for Nurses Conference 2008 6<sup>th</sup> - 7<sup>th</sup> November 2008**

Venue: Harrogate Majestic Hotel, Harrogate - NLCFN Members Only

Website: [www.nlcfn.co.uk](http://www.nlcfn.co.uk)

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**European Society for Therapeutic Radiology and Oncology (ESTRO)  
6<sup>th</sup> - 8<sup>th</sup> November 2008**

**Advanced Teaching Course on Multidisciplinary Treatment of Lung Cancer**

**Venue: Vilamoura, Portugal**

**Website: [www.estro.be](http://www.estro.be)**

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**7<sup>th</sup> Annual BTOG Meeting 2009  
28<sup>th</sup> - 30<sup>th</sup> January 2009**

**Venue: Clontarf Castle, Dublin**

**Website: [www.btog.org](http://www.btog.org)**

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**Perspectives in Lung Cancer  
6<sup>th</sup> - 7<sup>th</sup> March 2009**

**Venue: Crowne Plaza Brussels, Belgium**

**Website: [www.perspectivesinlungcancer.com](http://www.perspectivesinlungcancer.com)**

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**Postgraduate Course in Lung Cancer  
16<sup>th</sup> - 17<sup>th</sup> March 2009**

**Venue: Clinical Education Centre, Glenfield Hospital, Leicester**

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

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**Postgraduate Course in Malignant Pleural Mesothelioma  
18<sup>th</sup> March 2009**

**Venue: Clinical Education Centre, Glenfield Hospital, Leicester**

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

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**13<sup>th</sup> World Conference on Lung Cancer**  
**31<sup>st</sup> July 2009 - 4<sup>th</sup> August 2009**

**Venue: San Francisco, USA**

**Website: [www.2009worldlungcancer.org](http://www.2009worldlungcancer.org)**

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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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