

MESOTHELIOMA UK

National Macmillan Mesothelioma Resource Centre

Patient & Carer Newsletter

Issue 5 – February 2009

Welcome to Issue 5 of the Patient & Carer Newsletter.

I hope that the information in this newsletter is useful.

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

Please Note: Mesothelioma UK undertakes no responsibility for the accuracy of any information contained in non-related websites or given by non-related organisations.

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Free Prescriptions for Cancer Patients

Macmillan has been campaigning to ensure cancer patients do not have to pay prescription charges since 2005.

From 20 January 2009, cancer patients can pre-apply for an exemption certificate which will be valid from 1 April 2009. To apply, patients should complete form FP92A available at their doctor's practice or NHS Trust oncology department. Certificates are valid for 5 years and will be renewable for patients still receiving treatment for cancer or the effects of cancer treatment.

Exemption certificates will be issued to those, who in their doctor's judgement are receiving treatment for:

- cancer;
- the effects of cancer; or
- the effects of current or previous cancer treatment.

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

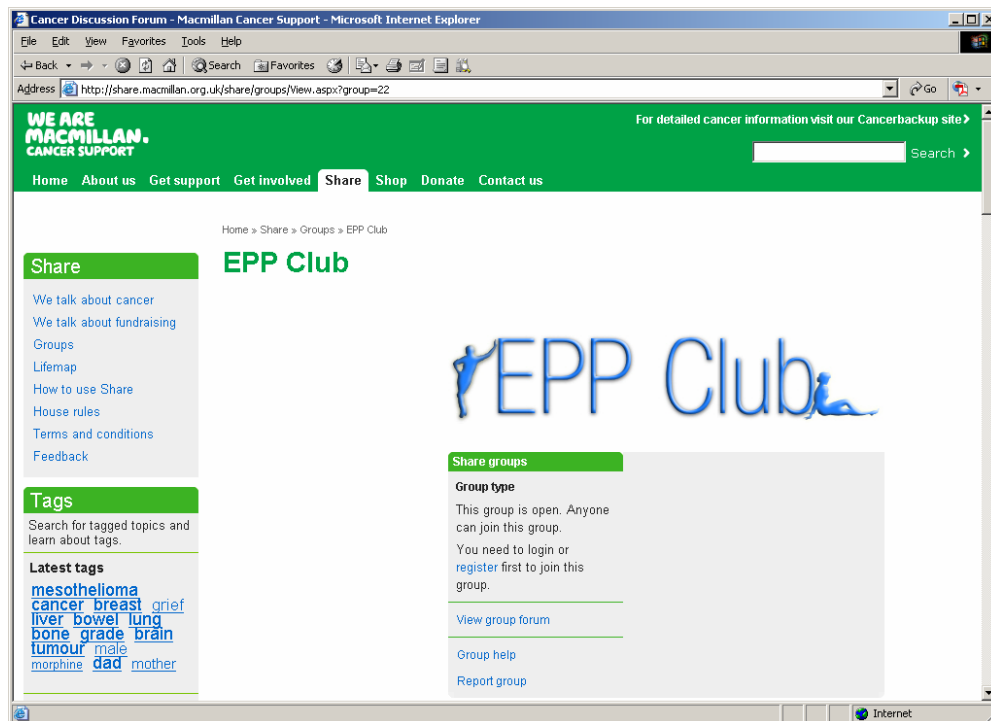
Mesothelioma News

Distribution of Hand held Fans by June Hancock Mesothelioma Research Fund

Hand held fans can be a useful aid for mesothelioma patients who experience shortness of breath. Other self-help techniques can be found on our website, www.mesothelioma.uk.com. The June Hancock Mesothelioma Research Fund will be distributing hand held fans to various support groups and lung cancer nurse specialists to give to patients. Fans will be provided free of charge and batteries can also be supplied if required. Your lung cancer nurse specialist or support group can obtain free fans from June Hancock Mesothelioma Research Fund or by emailing Adrian.Budgen@IrwinMitchell.com

EPP Club is available on the Macmillan Website

A discussion forum/club has recently opened on the Macmillan website for Extrapleural Pneumonectomy (EPP). If you would like to join the group you can register at <http://share.macmillan.org.uk/share/groups/View.aspx?group=22>



News story from Australia and Portrait Collection

Link to news story <http://www.smh.com.au/articles/2008/11/25/1227491548387.html>

A North Sydney photographer Chris Ireland has produced a collection of portraits (called *Breathe*) of women who have lost their husbands to asbestos related diseases. The portraits can be viewed online at www.chrisirelandphotography.com

“Dust” – the story of the trial against J W Roberts, Armley 15 July 2009 to 18 July 2009 at Courtyard Theatre, West Yorkshire Playhouse

In 1993 June Hancock was diagnosed with mesothelioma, exposure to asbestos occurred when she was a child in 1930s Armley. Already ill June took to trial J W Roberts, whose factory had put asbestos dust into the heart of Armley. June’s mother also died of mesothelioma. “Dust” is the story of that trial, drawn from trial transcripts, interviews and letters. Booking at https://www.wyp.purchase-tickets-online.co.uk/public/show_events_list.asp or you can telephone Tel: 0113 213 7700

Legal News

Law Firm Recovers Value of Hospice Care for a Mesothelioma Patient

It was reported on 12 December 2008 that a law firm had successfully recovered compensation for the cost of a claimant's hospice care. This case is very important as hospices are generally funded by charitable donations.

Lung Disease Compensation Announcement

An announcement on the issue of compensation for negligent exposure to asbestos for people with pleural plaques is expected soon. Pleural plaques are scarring of the lungs caused by exposure to asbestos. The issue was raised at Prime Minister's question time and PM Gordon Brown confirmed there would be an announcement very soon. In 2007 the House of Lords ruled that pleural plaques would no longer be compensated. Mr Brown recently said "The Secretary of Justice has been looking at this matter and talking with his colleagues' right across government about the implications of what we can do and I can assure you there will be an announcement very soon".

Extracted from an article in Doncaster Today – Wednesday 11 February 2009

Insurance and Mesothelioma Claims Legal Case

Written by Helen Ashton, Solicitor

The High Court in London was asked to decide in Summer 2008 whether certain insurance companies should pay out in mesothelioma claims. 6 test cases were considered by Mr Justice Burton during a 9 week trial throughout June and July. The cases all concerned the question of whether employees who had been exposed to asbestos when they were at work, could claim against their employer's liability insurance policy if, many years later, and after they had left that employment they developed mesothelioma. Employers take out insurance to cover them against claims from employees for injuries caused to them by employers' negligence for accident or disease. For decades, insurers have paid claims for mesothelioma on the basis that it is the policy in the year, or years the employee is exposed to asbestos which responds to pay the claim. This was the industry's practice, regardless of whether the words in the insurance policies covered employers for injuries or diseases "caused", "sustained", or "contracted" during the policy period. In 2006, 4 former insurance companies* stopped paying claims. Earlier that year, an appeal court had decided that a mesothelioma injury did not "occur" until the mesothelioma emerged. This was thought to be about 10 years before the illness could be diagnosed. Although the case involved a different type of insurance, these insurers argued that the words "injury sustained" and "disease contracted" meant the same as "injury occurring" and so the insurer on cover at the time of the emergence of the mesothelioma should pay the claim and not the insurer on cover at the time of the negligent exposure to asbestos. The question was crucial because often, by the time mesothelioma emerges, the employer is no longer in business and, consequently, there is no insurance in place to pay the claim.

The judge decided that the mesothelioma "injury" in fact happens about 5 years before it is diagnosed and not the 10 years previously decided.** He also decided that there was no difference between the meaning of the words "injury sustained", "disease contracted" and "injury occurring" per se. However, because employers' liability insurance has developed in a particular way and, because the commercial purpose of employers' liability insurance is to cover the activities of the employer so that the insurance covers employees for injuries suffered as a result of employers' negligence, he decided that the phrases used were intended to read "injury or disease caused". Caused being the exposure to asbestos which led to the development of the mesothelioma. The 4 former insurance companies, who were unsuccessful, have since appealed Mr Justice Burton's decision to the Court of Appeal. It is hoped that the appeal will be heard in July 2009. Until the issue has been finally decided by the courts, cases against the insurers involved remain on hold.

*The 4 former insurance companies involved are: The Builders Accident Insurance Company Ltd (now BAI (in Run Off) Ltd), The Independent Insurance Company Ltd (in provisional liquidation), Excess Insurance Company Limited and Municipal Mutual Insurance Limited.

** This point may be subject to a cross appeal.

Asbestos in Schools

Written by Michael Lees - 23 January 2009

- The Government acknowledge that children are particularly vulnerable to the risks of asbestos.
- Air tests have shown that in some schools common everyday classroom activities such as slamming a door or hitting a wall can release cumulatively dangerous levels of asbestos fibres.
- MPs, the chairman of the parliamentary health and safety committee, the teaching unions, Mesothelioma UK, the Asbestos Victims Support Forum, leading thoracic consultants, a leading occupational hygienist, the June Hancock Mesothelioma Research Fund and others have requested that the Government undertakes a national audit of the extent, type and condition of asbestos in schools, then carries out an assessment of the risks to the occupants.
- Government Ministers have refused.
- In January Freedom of Information requests from the Manchester Evening News determined that 903 of the 1,043 schools in Greater Manchester contain asbestos, and a similar request from the BBC determined that 554 of the 599 schools in Kent contain asbestos.
- Government policy is that so long as asbestos is in good condition and not likely to be disturbed then it is safer to leave it in place and manage it rather than removing it. However frequent asbestos incidents in schools prove that far too many are not managing their asbestos.
- Because of this the Government has been asked to reinstate a campaign to improve the asbestos management in schools.
- Government Ministers have again refused.
- The numbers of teachers dying from mesothelioma has increased year on year, 178 school teachers died of mesothelioma between 1980-2005, 64 of those being between 2001-2005. If teachers in higher and further education are included then 272 died in the same period. Sadly the teachers' deaths are likely to be the tip of an iceberg. There is no record of how many children have been exposed to asbestos at school and have subsequently died, that is because of the long latency their deaths are recorded under whatever occupation they had at the time.
- Twenty five years ago the USA carried out an audit and risk assessment. They estimated that 1,000 occupants of schools would die of asbestos exposure, 90% being amongst people who had been exposed as children.
- Large amounts of amosite were used in the construction of UK schools, crocidolite was also used. Much has deteriorated.
- Professor Peto's latest research shows that "*The lifetime risk in British men and women who report no potential asbestos exposure is four times the background (almost 1 in 1,000), suggesting that mesotheliomas were caused by unsuspected asbestos exposure in a wide range of occupational and non-occupational settings.*" The UK has "*the highest mesothelioma rate in the world and five times that in the US in men born between 1940-1955.*" He concludes that this "*extraordinary*" death rate has been caused by the extensive use of amosite in the UK.
- What must never be forgotten is that every adult who has died of mesothelioma attended school as a child. If they were exposed to asbestos even at very low levels over a prolonged period at school, then that could have initiated the process, with each additional low level exposure being cumulative, with each contributing to the likelihood of a tumour developing. As the latency for low level exposure can be very long, if no further exposure occurred after they left school then perhaps in most cases a tumour would never have fully developed. However because they were then exposed to additional asbestos fibres later in their job as perhaps a plumber, electrician or carpenter, the additional fibres added to the earlier ones, cumulatively contributing to the process until mesothelioma eventually developed.

The corollary is that if no asbestos exposure had occurred at school and instead the first exposure was as an adult, then it is possible that their mesothelioma might have developed many years later than it actually did. Perhaps it might not have developed at all.

News from Mesothelioma Patients and their Carers, Relatives and Friends

Walk for Len Challenge 2009 - www.walkforlen.com

"The Challenge is to walk the length of the Cotswold Way in six days in memory of my great friend and retired Police Officer Graham 'Len' Hutton and to raise money for the June Hancock Mesothelioma Research Fund, the disease that so sadly took Len from us in December 2008 aged 66." John Barnes, Challenge organiser.

Mesothelioma Patient Campaigns for Chemoembolization Treatment in the UK

Debbie Brewer, a Mesothelioma patient is asking for support to the petition for chemoembolization treatment in the UK for Mesothelioma, to see Chemoembolization trialled in the UK and become a treatment that would be offered to Mesothelioma patients. The link to the petition can be found on the 10 Downing Street site - <http://petitions.number10.gov.uk/Mesothelioma/>

*Please note that Mesothelioma UK does not endorse or recommend chemoembolization as a treatment for mesothelioma. Mesothelioma UK recommends that patients discuss the appropriateness of treatments with the doctor or hospital team who is currently caring for them.

Campaigning News

CORONERS REFORM BILL

The British Lung Foundation (BLF) welcomes the Government's inclusion of the Coroners and Justice Bill in the Queen's Speech, and the much needed reforms to the current coroners system that it will bring about. As an organisation that works to represent people with the asbestos related lung cancer, mesothelioma and their families the British Lung Foundation has become aware of the flaws in the coroners system, and the needless distress that it can cause to already grieving families. When someone dies from mesothelioma it is classified as 'an unnatural death' and it is therefore required that a coroner carries out an inquiry. If the death occurs outside of the coroner's working day (i.e. on evenings and weekends) the police have to start the investigation immediately.

This can lead to the bereaved relatives receiving visits from uniformed police, in marked cars, sometimes in the middle of the night. This is highly distressing, and can lead to relatives feeling that they are under suspicion. The Coroners and Justice Bill will allow the creation of national standards which should end such practices and will help to ensure these procedures are made more sensitive to the needs of bereaved families. This will be underlined by the proposed Charter for the Bereaved which will accompany the bill, and specifically calls for the creation of national standards on Mesothelioma deaths. Coroners will also have better medical support and advice, including the appointment of a Chief Medical Adviser who will give advice on specialist medical issues such as mesothelioma. Michael Clapham MP who has supported the British Lung Foundation's campaign said, "There is an urgent need for a new Coroners and Justice Act. This would provide an opportunity to improve and ensure consistency in dealing with mesothelioma deaths across the entire UK. "The system needs to be more friendly and considerate to the grieving process when a mesothelioma death occurs." Dame Helena Shovelton, Chief Executive of the British Lung Foundation, said: "The current coroners system can cause unnecessary distress to people already going through a very difficult time in their lives. We are extremely happy that the Coroners Bill will now be brought forward to help end these practices, and we look forward to working with the Government to improve coroner's procedures". The British Lung Foundation has been campaigning on this issue since 2006, and has gathered a considerable amount of popular and political support. A recent Early Day Motion tabled by Michael Clapham MP has been signed by 116 MPs.

David.Buckle@blf-uk.org

Mesothelioma UK believes that this is an issue that is raised by many mesothelioma patients and carers and can add to the distress and upset at an already difficult time. Mesothelioma UK is included on the stakeholder list for the reform of the Coroner system and will be kept informed regarding the progress of the bill.

Petition for National Centre for Asbestos-Related Disease UK By the Sheffield and Rotherham Asbestos Group (SARAG)

In the UK, almost every penny raised for mesothelioma research is donated by the relatives, family and friends of mesothelioma sufferers, who give money each year to two mesothelioma charities for research into better treatments. The UK Government gives virtually nothing to mesothelioma research regardless of the fact that 60,000 people will develop mesothelioma over about the next 25 years. The experience of other countries like Australia shows what can be achieved when research is properly resourced. Government funding for a National Centre for Asbestos Related Disease in the UK for research into better treatment is long overdue and *urgent*.

You can obtain a copy of a petition by calling SARAG on 0114 2823212. SARAG will be collecting signatures until 27 February 2009.

Media Request

Cancer Research UK Request for Patients or Families Willing to Speak to the Media

Cancer Research UK is often approached by journalists who want to speak to people affected by mesothelioma and they have approached Mesothelioma UK to ask if any patients would be willing to help. Cancer Research UK would like to work with people on a one to one basis and they would guide them through the experience of sharing their story.

You can contact Mary Ryan, Patient Liaison Manager at Cancer Research UK - Tel 0207 061 8303
For more information www.cancerresearchuk.org/shareyourstory

Photojournalist Request for Patients Willing to be Interviewed and Photographed

A photojournalist based in Nottingham is looking to interview and photograph mesothelioma sufferers in the East Midlands for a planned series of articles to go in national newspapers and magazines. If you know of anyone who would be willing to be interviewed or would like further information, please contact Neil Hodge via email at neil@neilhodge.co.uk or on 0115 9469311.

Mesothelioma UK Charitable Trust

**Registered Charity No 1126083
Registered on 26 September 2008**

The Charitable Trust exists to raise funds and provide financial support to the National Macmillan Mesothelioma Resource Centre (known as Mesothelioma UK) and to other initiatives to promote and protect the health of sufferers of mesothelioma. You can contact the Mesothelioma UK Charitable Trust on 0800 169 2409 or email mesothelioma.ukcharity@uhl-tr.nhs.uk

If you would like to make a donation to Mesothelioma UK Charitable Trust please make cheques payable to "Mesothelioma UK Charitable Trust" and forward to:-

Dawn Mckinley - Operational Manager
Mesothelioma UK Charitable Trust
Hospital Management Offices
Glenfield Hospital
Leicester
LE3 9QP

Donations received will help Mesothelioma UK to provide information to patients with Mesothelioma and their carers and relatives.

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

MESOTHELIOMA UK
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