

Issue 7  
August  
2009

# Mesothelioma UK

*National Macmillan Mesothelioma Resource Centre*

## Patient & Carer Newsletter

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Welcome to Issue 7 of the  
Patient & Carer  
Newsletter.

**4<sup>th</sup> Mesothelioma UK  
Patient and Carer Day 2009**  
**Date: Saturday 3<sup>rd</sup> Oct. 2009**  
**Venue: Life Conference  
Centre, Newcastle**

We will be holding the 4<sup>th</sup> Patient and Carer Day in Newcastle. I look forward to this day as it gives me the chance to meet patients and carers who have contacted Mesothelioma UK. It also gives mesothelioma patients and carers the chance to meet and share experiences with others affected by the disease and to give up-to-date, unbiased information on treatment and care.

Places at the day are free of charge for mesothelioma

patients, their carers, relatives and friends. A charge will be made to voluntary organisations, health professionals and related industry representatives who wish to attend.

This event is kindly supported by a grant from the Mick Knighton Mesothelioma Research Fund.

A registration form can be found on the next page. Full details are available on the website:

([www.mesothelioma.uk.com](http://www.mesothelioma.uk.com))  
or by calling the Helpline on 0800 169 2409.

**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.***

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](mailto:mesothelioma.uk@uhl-tr.nhs.uk)

Website: [www.mesothelioma.uk.com](http://www.mesothelioma.uk.com)



## Pain Relief for Mesothelioma Patients

A procedure called a Percutaneous Spinal Cordotomy may help relieve pain that has not responded to conventional pain medicines. The procedure involves heating some of the pain nerves in the spinal cord that transmit pain information to the brain. It involves placing an electrode (about the size of a blood test needle) into these pain carrying pathways, using special x-ray guidance. It is

done under a local anaesthetic; the patient is awake so that they can communicate any sensations felt during the procedure. Patients who have been treated with this procedure can gain long term pain relief (months to years). Sometimes the procedure can be unsuccessful because the pain nerves cannot be identified safely. Any risk should be discussed with the doctor. There are currently

three centres offering a Percutaneous Cordotomy service to patients - these cover the South, North and Midlands. Further details about this procedure can be found on the website, [www.mesothelioma.uk.com](http://www.mesothelioma.uk.com). Mesothelioma UK recommends that patients discuss the appropriateness of treatments with the doctor or hospital team who is currently caring for them.

## Carers Direct – Information, Advice and Support for Carers

Carers Direct ([www.nhs.uk/carersdirect](http://www.nhs.uk/carersdirect)) is a new service launched on NHS Choices as part of the government's New Deal for Carers. This service is designed to improve support

for England's growing number of carers. It provides carers with information, advice and support including guidance on the different stages of caring, information for claiming benefits, advice for

young carers, contact details for local authorities and support groups, news articles and case studies with videos. The free telephone helpline is open 7 days a week on 0800 802 0202.

## 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](http://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

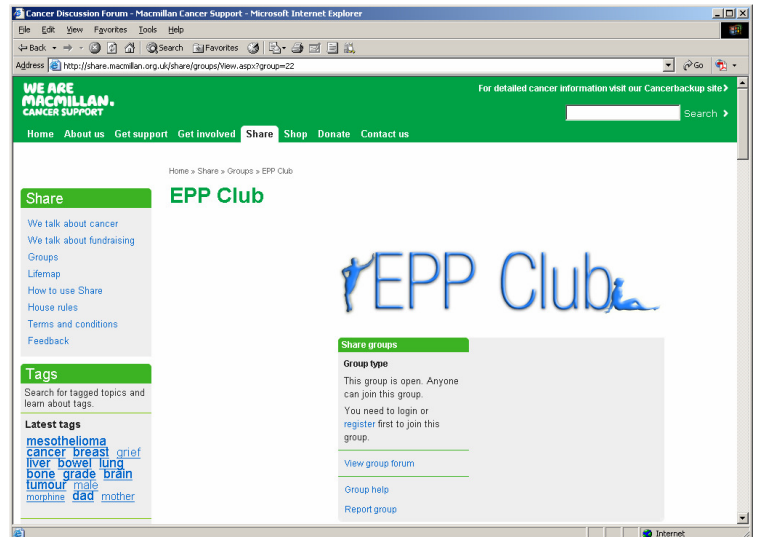
supplied if required. Your lung cancer nurse specialist or support group can obtain free fans from June Hancock Mesothelioma Research Fund or by emailing [Adrian.Budgen@IrwinMitchell.com](mailto:Adrian.Budgen@IrwinMitchell.com)

## EPP Club is available on the Macmillan Website

A discussion forum/club 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>



## Coroners and Justice Bill

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 cause distress to grieving families. 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.

### Latest Update:

See the following link for the fourth bulletin about the

Coroners and Justice Bill's progress through Parliament:

<http://fflm.ac.uk/upload/documents/1248454032.pdf>

**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.

Helpline: 0800 169 2409 Fax: 0116 2502810

Email: [mesothelioma.uk@uhl-tr.nhs.uk](mailto:mesothelioma.uk@uhl-tr.nhs.uk)

Website: [www.mesothelioma.uk.com](http://www.mesothelioma.uk.com)

## Mesothelioma UK Charitable Trust

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](mailto: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:- Jill Lemon, Fundraising

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.*

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

## Cancer Sufferer Set to Win Bet on Own Life

A man with terminal cancer is set to win thousands after betting he would not die before June. Jon Matthews will collect £5,000 from bookmakers after he beat the odds of surviving.

He scooped £5,000 on 1 June 2008 after placing a bet with William Hill that he would not be dead by then. He also made a further bet that he would live beyond 1 June this year.

A spokesman for William Hill said, "Never in 30 years in the business have I been so pleased to pay a winning client £10,000".

Mr Matthews, a widower, has Mesothelioma and was told

by Harefield Hospital in Middlesex that their longest surviving patient lived for 25 months after diagnosis.

If Mr Matthews survives until June 2010 he will win another £10,000 after placing another bet.

Mr Matthews said "when I was diagnosed I was told Mesothelioma was a death sentence. I wasn't that fussed because everyone has to die some time. But the interesting thing for me was how long it would take, would it take weeks or years", he explained.

He plans to donate most of his winnings to cancer charities.

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*"Never in 30 years in the business have I been so pleased to pay a winning client £10,000" said a spokesman for William Hill*

## Charity Cyclists Complete 1,200 Mile Breathtaking Journey

Three cyclists have completed a gruelling 1,200 mile bike ride from Glasgow to Hampshire and raised £14,000 for Mesothelioma research.

Specialist solicitors Katrina London, Paul Granville and campaigner Jason Addy cycled through some of the regions whose communities have been most hit by Mesothelioma.

Southampton and Portsmouth are particularly badly affected due to industries such as shipbuilding, engineering and the railway works.

The funds raised for the

Hampshire Asbestos Group will be used to open a special centre for research into asbestos-related conditions. Diane Salisbury, co-founder of Hampshire Asbestos Support said:

*'We were delighted to greet the campaigners giving them the welcome they deserved for such a phenomenal achievement. We are seeing increasing incidences of asbestos-related conditions including Mesothelioma.'*

The 'Breathless Journey' cycle ride finished with a heroes' welcome at Southampton's Mayflower Park.

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*"We were delighted to greet the campaigners giving them the welcome they deserved for such a phenomenal achievement".*



## Asbestos Campaigners Petition Downing Street



*Petition being presented at Downing Street*

On Wednesday 20 May, a delegation of campaigners and MP's presented a petition of over 22,000 signatures to 10 Downing Street calling on the government for funding for asbestos cancer research in the UK.

In just two short months prior to Action Mesothelioma Day this year, Asbestos Victim Support Groups throughout the UK gathered an overwhelming 22,000 signatures, which was presented to 10 Downing Street at 4.00 pm on Wednesday 20 May.

The petition calls for government funding for a National Centre for Asbestos Related Disease (NCARD) to be established in the UK. This would be an organisation of existing and new research groups around the UK and Ireland working closely together as a virtual centre rather than a bricks and mortar research unit. The asbestos cancer mesothelioma has the second worst survival rate of all cancers YET - it *"Is the least researched of the top twenty cancers in the UK"*

John Edwards: Consultant Thoracic Surgeon and Chair of the British Mesothelioma Interest Group and one of the petitioners says:

*"Researchers are desperate for funds to develop life saving treatments - mesothelioma is far*

*and away the least researched of the top twenty cancers in the UK. Funding for a UK National Centre for Asbestos Related Diseases is a priority. Such a virtual institution would encourage collaboration between current and future researchers and stimulate trans national research to generate future treatments to prolong and save lives."*

Tony Whitston: Chair - Asbestos Victims Support Groups Forum - UK says:

*"In the US, mesothelioma has been given research priority to bid for mesothelioma research projects from the defence research budget in recognition of the thousands of veterans exposed to asbestos in service and in naval shipyards. In Australia, the government has given \$6 million to fund a research centre. Society has a moral obligation to stand by those who have lost their health and their lives in creating this country's wealth."*

A mesothelioma sufferer was among the petitioners that also included:

Rt Hon Nick Brown MP; Mr Dave Anderson MP; Mr Michael Clapham MP; Mr John Edwards, Consultant Thoracic Surgeon; Mrs Chris Knighton, Mick Knighton Mesothelioma Research Fund; Liz Darlison, Mesothelioma UK and Paula Walker, Asbestos Support Groups Forum UK.

## Mick Knighton Mesothelioma Research Fund Award Recipient 2009

### Research Study: Treating Malignant Mesothelioma with Stem Cells

Despite major advances in several cancers over the past thirty years mesothelioma is still incurable and all those affected will die of the disease. Dr Janes has recently demonstrated that Mesenchymal Stem Cells (MSC) usually found in bone marrow preferentially travel to and integrate into tumours where they form some of the infrastructure called stroma. He has shown in a metastatic lung cancer that these cells can deliver a therapy to the tumour cells that result in the death of tumour cells but

not the normal surrounding tissue cells. He now wants to deliver this therapy to Mesothelioma. When using this therapy in lung cancer models, initial experiments shown control of the growth of tumours and has in almost 40% of cases eliminated them. If successful this may introduce a new era of treatments for Mesothelioma patients. Mesothelioma is particularly suitable to this type of therapy because the cells can be delivered by a tube directly into the chest avoiding problems encountered in trying to target other cancer cells around the body.



*Dr Sam Janes, Senior Lecturer & Honorary Consultant, University College London*

## Compensation Claims

If you have Mesothelioma and it can be proved that someone else was responsible for your asbestos exposure, you may be able to take legal action to claim compensation.

The estate and dependants (wife, partner, children and others) of a Mesothelioma sufferer can also take legal action to claim compensation. Claims by the dependants can be commenced following the death of the Mesothelioma sufferer.

Legal action taken against

former employers is mainly dealt with by the employers' insurance companies and action may still be possible even if the employer no longer exists provided the employer's insurance company can be traced. If you are thinking of making a claim for compensation it is advisable to seek legal advice quickly as there is a statutory 3 year limit for making a claim. It is important that the Mesothelioma sufferer's evidence is recorded in statement form as soon as possible. The Mesothelioma sufferer's recollection of events can be essential to

the success of a claim. The 3 year limit applies from when you knew you had an asbestos related disease and also 3 years after the death of someone with Mesothelioma. However, the 3 year limit is not always strictly enforced - your solicitor will be able to advise you on this matter.

For more information go to the following link on the Mesothelioma UK website:

<http://www.mesothelioma.uk.com/index.php?pageno=59>

# THE DAY OF ROCKENING

A CELEBRATION of Horsham's finest music and art.

Saturday 12 September 2009

The Capitol, North Street, Horsham, West Sussex RH12 1RG

The DAY OF ROCKENING has been organised to celebrate the memory and astonishing work of the late Graham Ansell who was a linchpin in Horsham's music scene for nearly 30 years. Graham passed away in April 2007 just 9 months after being diagnosed with mesothelioma. He was just 48 and leaves a wife Mandy, and 3 children. In Graham's memory, all proceeds from this event will be donated to Mesothelioma UK and Bart's Mesothelioma Research

You are invited to join us in a unique music

extravaganza featuring some of Horsham's finest musicians, past and present, to celebrate 30 years of great music, great art and great memories. The event starts at midday with an exhibition of rock legends by local artist Greg Hart; the Music Timeline exhibition featuring some of Horsham's legendary bands dating back over 30 years and the DAY OF ROCKENING auction featuring exclusive collectable lots from the world of rock and roll including a signed Paul Reed Smith Tremonti SE electric guitar. Live acoustic music starts at 5pm in the bar area followed at 7pm by the main event in the Theatre, featuring:

## ALLSTARZ

a collaboration of some of Horsham's finest musicians playing a one off show including ex members of

*Bush, Ultravox, Flairz, Boogie Wonderland, Limehouse Lizzy, Decadent Dance, Goodfellas, 17Black*  
CLASH CITY ROCKERS - back together for one night only  
BAD BOY BOOGIE - performing their stunning tribute set to AC/DC

TICKETS £10 FROM  
The Capitol Box Office  
01403 750220

[www.thecapitolhorsham.com](http://www.thecapitolhorsham.com)

FREE ENTRY for bar shows and exhibition

Full details of artists and auction lots at:

[www.myspace/dayofrockening09](http://www.myspace/dayofrockening09)

and

[www.dayofrockening.com](http://www.dayofrockening.com)

**Mesothelioma Patient Support Groups**

**Barrow Asbestos Related Disease Support (BARDS)**  
Tel: 01229 580305 or 01229 430111

Cumbria. A service for patients with asbestos related disease, their families and carers. It is provided in St Mary's Hospice in collaboration with the Benefits Agency, Social Services, local unions, the Citizens' Advice Bureau and expert lawyers. Meets one day a month in St Mary's Hospice Social Care Centre, Lesser Kings Hall, Hartington Street, Barrow in Furness (next to Furness Gymnastics) 2pm - 4pm.

**East London Mesothelioma Support (ELMS)** Freephone

Helpline: 0800 8766773 Between 5pm - 10pm East London (Newham, Tower Hamlets, Hackney) Services: Support, guidance and information for patients, carers, relatives and friends.

**Hampshire Asbestos Support & Awareness Group (HASAG)**

Contact Lynne on 07940 328637 or Diane on 07792 543426 Meets 2nd Thurs each month at 10:30 am at T & G (Transport & General), also known as UNITE, Transport House, 15/16 The Avenue, Southampton, S017 1XF. HASAG also meets on 4th Thurs of each month at 10:30am at The Hilton Portsmouth, Eastern Road, Farlington, Portsmouth, PO6 1UN. These group meetings are for sufferers of all asbestos related diseases

and/or their families including the bereaved.

**Mesothelioma Self Help Group** Tel: 0191 263 7386 (Mick Knighton Mesothelioma Research Fund).

Aims to provide information and support to sufferers and their families. Offers a warm, friendly environment and welcomes all whose lives have been affected by Mesothelioma. Meets at Sir G B Hunter Memorial Hospital in Wallsend on last Fri of each month 11am-1pm. Refreshments provided.

**Medway/Swale Lung Cancer & Mesothelioma Support & Information Group** Contact Frances McKay, Macmillan Lung /Mesothelioma Nurse, Medway Maritime Hospital on 01634 825212, Caroline Williams, Macmillan Lung Nurse, Medway Maritime Hospital on 01634 825391 or Pat Cameron, Domiciliary Team Nurse, Wisdom Hospice on 01634 830456 - Offers a welcome environment providing mutual support and information for Lung Cancer / Mesothelioma patients/carers. Meets first Tues of each month from 3pm-4.30pm at the Day Centre, Wisdom Hospice, St Williams Way, Rochester. Refreshments are available and transport can be provided.

**Mesothelioma Support Group at Royal Marsden Hospital, Surrey** Contact Sally Moore on 020 8661 3150 Hands of Time

**Mesothelioma Support Group at Royal Marsden Hospital, Surrey**

Contact Sally Moore on 020 8661 3150 Hands of Time

**Mesothelioma Support Group** - meets 1st Tues of month 11am-1pm Richard Dimbleby Cancer Information & Support Service, 2nd Floor, Gassiot House, St Thomas Hospital, London, SE1 7EH. Open to patients/carers. Refreshments provided. Contact Dimbleby Cancer Care on 0207 1885918.

**Mesothelioma Support Group at Guy's Hospital, London** Contact Kirsty Morton on 020 7188 4739

**Mesothelioma Support Group in Leicester** Contact Mesothelioma UK on 0800 169 2409

**Swindon & South West Support Groups** Contact Angela Whitehorn on 01793 336482 group for widows /partners of asbestos sufferers. Meets monthly for friendship. mutual support & practical help for those nursing a family member with asbestos disease. Contact Shirley Hollister on 01793 496398 - for those suffering from asbestos disease & their partners. Gives lectures by health professionals on various aspects of asbestos disease & there is a free lunch. Meets for mutual information & support. Contact Maureen Seabrook 01822 880233 - Wives & Widows Group Exeter, meets monthly for friendship & mutual support.

**Mesothelioma Support Group at Papworth Hospital, Cambridge** Contact Gerry Slade, Mesothelioma Specialist Nurse on 01480 830541 Ext 4889 - Meets at Papworth Hospital every 6 weeks for patients/ carers. Talks have included relaxation, breathlessness and complementary therapies. A separate meeting every six weeks is specifically for carers so they can share their concerns and experiences with others in a similar situation. Refreshments provided for both meetings.

**Southend Lung Cancer & Mesothelioma Information & Support Group** - An informal group providing an opportunity to meet others in a similar position. Meets 1st Weds of month 12.30pm-2.00pm at Coleman Street Chapel, Coleman Street, Southend. Light refreshments provided. Contact Jolly Barber, Jo Phelps or Michelle Palmer on 01702 435555 Ext 6835.

**West Hertfordshire Trust Support Group** Contact Linda Charalambous on 01923 217010. For all West Hertfordshire Trust lung cancer / mesothelioma patients. Held 1st Tues of month 2-4pm at Stanborough Centre, 609 St Albans Road, Garston, Herts. WD25 9LJ. Includes refreshments, guest speakers, complementary therapies, advice, info. & support about disease, finances, treatments & what patients / carers would like to include.

## Macmillan Resources



Macmillan Cancer Line  
0808 808 2020  
Macmillan Benefits Line  
0808 801 0304

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](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](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](mailto:youthline@macmillan.org.uk)

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Helpline: 0800 169 2409 Fax: 0116 2502810

Email: [mesothelioma.uk@uhl-tr.nhs.uk](mailto:mesothelioma.uk@uhl-tr.nhs.uk)

Website: [www.mesothelioma.uk.com](http://www.mesothelioma.uk.com)