

Mesothelioma UK

National Macmillan Mesothelioma Resource Centre

Bulletin

July 2009 Issue 1

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Mesothelioma UK Update

Mesothelioma UK has continued being very active supporting the development of a national government supported research centre for asbestos related diseases. Clinical lead for this, John Edwards has written an update in this bulletin.

The Mesothelioma UK Charitable Trust which exists to raise money to fund the services provided by Mesothelioma UK; namely the helpline, website, educational events, newsletters etc has now appointed a full time marketing and fundraising coordinator, Jill Lemon who takes up her post on 6th July.

The Mesothelioma Nurse Action Team (M-NAT)

met in Manchester on 2nd June. It was an excellent day facilitated by Dr Helen Clayson that focused particularly on symptom management. The Mesothelioma UK/Royal Marsden on-line Mesothelioma degree and masters module has now been accredited by Thames Valley University and we will keep you informed of when this will become available.

The ChIMP project has now completed data collection. A final report is being written and the first presentation of data will be at the Perspective in Lung Cancer meeting in November 2009. An update is contained within this bulletin.

We are busy preparing for our annual Mesothelioma Patient and Carer Conference. This is being held in Newcastle on Saturday 3rd October 2009. A flyer is included in this bulletin for you to distribute far and wide.

Website and Helpline:
In the last quarter Mesothelioma UK has received 205 contacts via the helpline or email and there have been 1435 hits on the website.

M-NAT: The next M-NAT meeting will be held in London on 6th November.

Thank you for your continued support.

Liz Darlison



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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.

For more information contact Mr John Edwards, Consultant Thoracic Surgeon: 0114 226 9279 and Paula Walker, Secretary, ASG Forum UK on 01709 360 672 or 07913 392 049.



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National Centre for Asbestos Related Diseases – an update

"The journey of (over) a thousand miles starts with a single peddle..." Thus say Paul Glanville, Katrina London and Jason Addy, who are currently riding the length and breadth of the country on their inspired Breathtaking Journey (see page 7).

The journey towards reality for NCARD is a few miles down the road, but there is a long way still to go.

The NCARD Development Group has now had the opportunity to meet the front bench health teams of the three largest political parties. Awareness of the concept has certainly reached Cabinet level and the Prime Minister himself. Recently, we have had a series of meetings with researchers and officials from many organisations including the Department of Health, the National Cancer Research Institute and Cancer Research UK. Most recently, a significant meeting was held with all these organisations on 22nd June, which Prof Bruce Robinson, Director of the Australian NCARD, was able to attend, to our delight.

Each task in this journey is larger than that before. The next steps are:

- to prepare a Strategic

Document to distribute to Government, politicians and the various potential stakeholders

- to develop further the identity and "brand" of NCARD, in creating a website and a logo
- to increase awareness amongst the public and politicians
- to appoint an NCARD Project Manager

Ongoing assistance is essential and the financial support both received and pledged is vital in securing further progress. So too is grass-root activism. I am tremendously impressed by the fantastic response to the petition co-ordinated by the Asbestos Victims Support Groups Forum. To be able to see the large red box delivered at Number 10 Downing Street was truly moving. The pressure needs to continue, however. Potential grant funders - the Government included - need to see NCARD as a living entity, breathing fire and moving mountains, such that they feel that they dare not miss the excellent opportunity of coming onboard and providing significant financial support. In this regard, the effect of victims and their families in raising the issues in the press, through trade unions and in lobbying directly your local

MP is crucial. I can provide material to assist you in this, and hope that there will be full resources and information on the website before too long.

Seriously, though, we need your help.

We need a logo. Could you design one? We would receive gratefully any ideas that you might have, even if they are on the back of an envelope and need a bit of work to bring to fruition.

We need a website. Is there a volunteer who would be happy to design and create a professional web presence? Please do get in touch.

There have been a few tough moments for us as we battle with politicians, some of whom stare back blankly, offering little. But to know that we have the backing of thousands, nay, tens of thousands, of supporters drives us ever on. More up hill than down dale, for sure, but we have a strong wind behind us on our journey.

Mr John G Edwards
Consultant Thoracic Surgeon
Sheffield
john.edwards@sth.nhs.uk
01142 269 279



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Change of Date for Action Mesothelioma Day

You will be aware that the annual timing of Action Mesothelioma Day has been up for debate recently. After lengthy discussion and investigation into what is best for our

Mesothelioma community and what other national campaigns take place it has been decided that from 2010 onwards Action Mesothelioma Day will be the 1st Friday in July.

I hope this is agreeable to everyone and Mesothelioma UK will look forward to communicating far and wide events and activities that take place around the country to mark this



One of the events marking Action Mesothelioma Day 2009

Mesothelioma and Radical Surgery (MARS) Trial

The Mesothelioma and Radical Surgery (MARS) trial having reached the 50 randomisations to complete the feasibility study closed to recruitment in late 2008. I am pleased - through the Mesothelioma UK Newsletter - to be

able to thank all the patients, clinical teams, and the ICR staff, who have worked so hard. A paper documenting this achievement is accepted for publication in the Journal of Thoracic Oncology. It will be presented at the

World Lung meeting in San Francisco in August 2009 by Dr Michael Snee on behalf of the MARS trialists. Plans for MARS-2 are well underway and the first of the many hoops are being jumped through. By Prof. Tom Treasure. tom.treasure@googlemail.com

"I am pleased - through the Mesothelioma UK Newsletter - to be able to thank all the patients, clinical teams and the ICR staff who have worked so hard".



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MALCS

Mesothelioma And Lung Cancer Study - a postal survey

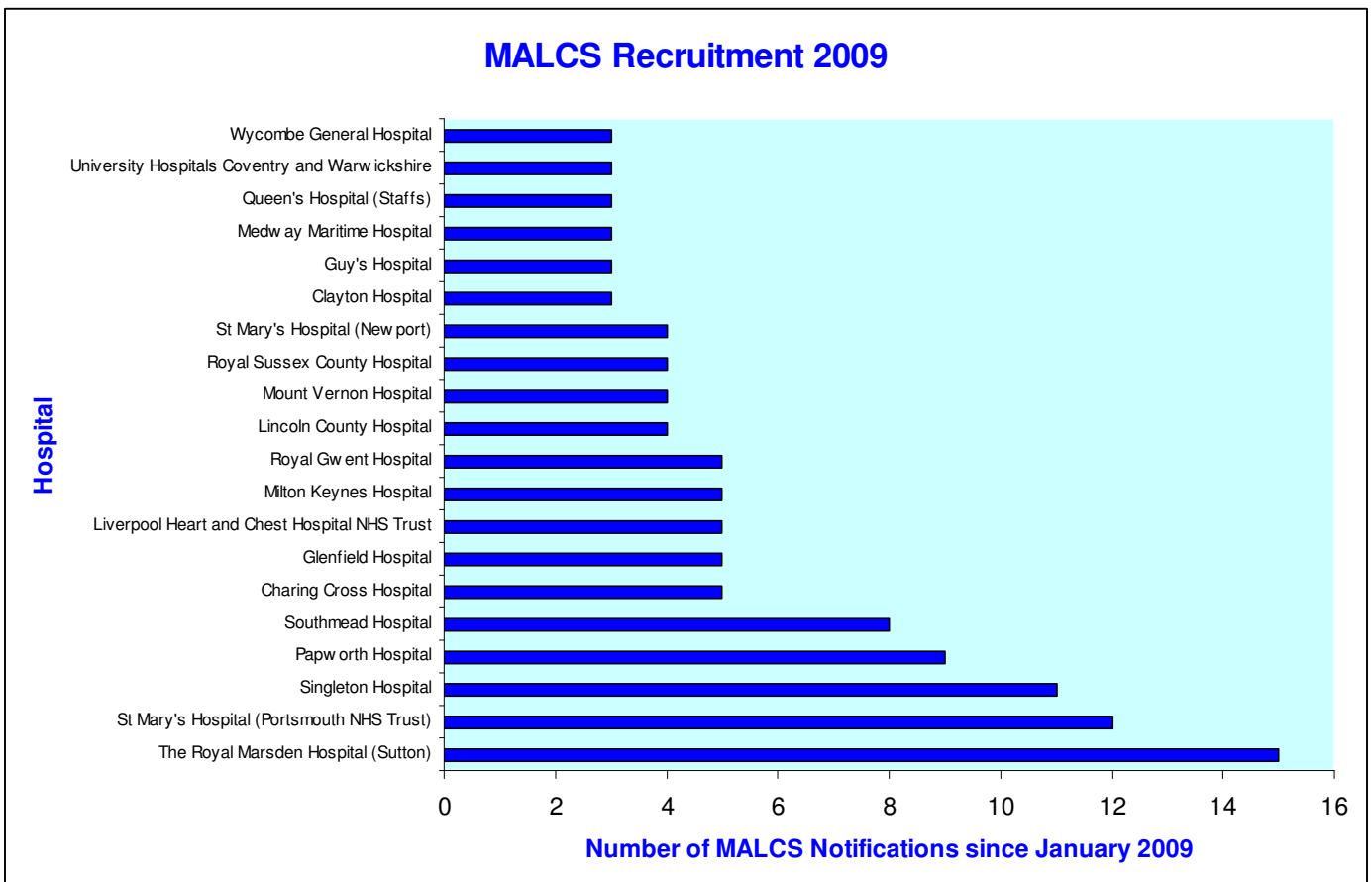
MALCS was set up over 10 years ago at The Institute of Cancer Research to estimate the mesothelioma and lung cancer risks associated with specific occupations and work practices across Britain. Data is collected by postal questionnaire. Our analysis of the first 622 mesothelioma patients and 1420 controls

recruited to this study has recently been published in the British Journal of Cancer (Br J Cancer 2009;100(7):1175-83), and we wish to continue recruiting patients until 2015. This MREC approved study is SSA exempt, and attracts NCRN funding. Since the second phase of recruitment began (in

2007), we have received completed questionnaires from 93 male resected lung cancer patients, 124 male mesothelioma patients and 55 female mesothelioma patients. We wish to recruit as many patients as possible to MALCS - the more we recruit, the more accurate our results - there is no recruitment ceiling.

We'd like to say a huge thank you to all current and past recruiters to MALCS and remind you all that we are still open for recruitment (to ongoing and new sites)

Centres who have notified the MALCS team of at least 3 eligible patients since January 2009 are shown below:



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..Cont'd from page 5

Thank you to these centres and all the other centres who have notified us of patients this year - please keep up the good work! NCRN funding is awarded for every patient notified to us (even if they don't send back the survey).

What does MALCS recruitment involve?

1. Giving eligible mesothelioma and lung cancer patients an information sheet and completing a 1-page notification form
2. Sending the notification form to

the MALCS team (SAE's are provided)

There is no monitoring and no further paperwork for you to do. When we receive the form, we write to the patient with the postal survey. The patient returns

the survey directly to us at the ICR.

For more information, please contact the MALCS team on 0208 722 4298 or by e-mail: MALCS@icr.ac.uk

Chemotherapy in Mesothelioma Project (ChiMP)

The ChiMP Project has now finished, if you have any outstanding data please send it in as soon as you possibly can. Don't forget to send your completed claims forms as these will not be processed after the 17th July 2009.

The response to this project has been phenomenal, 36 sites have completed data

and are now in the process of claiming for their chosen fund and a further 6 have completed and sent all their data so you need to send your forms in ASAP.

18 sites still have outstanding data, so please send yours!!!

736 patients have been registered with ChiMP over this last year, 17 of those

have been excluded for various reasons and there are 41 patients with no data at all, 30 patients still have outstanding data although that is steadily coming in and at present 678 patients are having their data analysed, so please feel very proud of yourselves, everyone has worked extremely

hard for this project even though you all have various time constraints. The ChiMP steering committee and I would like to thank you for your tireless contribution and making this project a success.

Jill Lemon
ChiMP

Project Manager



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Percutaneous Cordotomy

There are three current centres offering a Percutaneous Cordotomy service to patients, as of now. Respectively they cover South, North and the Midlands. They are all happy to have their details circulated. They are:-

1. Drs Derek Pounder, Mike Williams or Nick Campkin
The Pain Clinic
St Mary's Hospital
Milton Road
Portsmouth
PO3 6AD
Tel: 02392 286000 ext. 2536
Fax: 02392 866388
This is currently the main centre for cordotomies in the UK and is receiving ~120 new patient referrals per annum.

2. Dr Paul Cook
(Consultant in Palliative Care & Anaesthesia)
Room 21, Central Offices
Pennine Square
Royal Oldham Hospital
Rochdale Road
Oldham
OL1 2JH
Tel: 0161 656 1912

Fax: 0161 656 1929
e-mail: paul.cook@pat.nhs.uk
3. Dr Hugh Antrobus
Pain Clinic
Warwick Hospital
Warwick
CB34 5BW
Tel: 01926 495321 ext. 4738
Fax: 01926 482613
e-mail: hugh.antrobus@swh.nhs.uk

Each centre has its own patient information leaflets. At a minimum, full patient details are needed, including a patient contact phone number, their awareness of diagnosis and prognosis, current medication, disease spread & the other health professionals involved in their care. All three centres are happy to phone patients, to answer any referral or cordotomy queries, instead of a formal pre-procedure outpatient appointment. If the patients are geographically too distant this avoids the need for repeated travel to the cordotomy centre.

There may be other services developing in the coming months (I will keep you updated), but these are the current ones and have been running for over a year, at the minimum. The referral criteria are:-

Indications

- * UNILATERAL PAIN below the neck/collar line (C4 dermatome).
- * Uncontrolled by strong analgesia (opioid and non-opioid), or likely to become so shortly.
- * LIMITED life expectancy (< 2 yrs).
- * Must be able to LIE FLAT for 1 hour.
- * Must be able to CO-OPERATE, lie still.

Procedure performed awake under Local Anaesthetic (the patient must be conscious for sensory/motor testing to enhance safety, prior to radiofrequency lesioning). Small doses of intravenous painkillers can be given during the procedure if needed.

Best results - Chest wall, arm (unable to lesion above C4; less reliable, though

possible for pain below knee).

Contraindications

- * Current active Anticoagulation Warfarin etc. - please liaise with the cordotomy centre prior to referral to discuss management.
- Aspirin must be stopped for ONE week prior to the procedure date.
- Clopidogrel must be stopped for TWO weeks before the planned procedure date.
- * Local infection or metastasis at the site of procedure (just below the angle of jaw on the side opposite to the patient's pain).
- * Inability to co-operate and lie flat for 1 hour.

Examples

MESOTHELIOMA
Brachial plexus involvement e.g. Pancoast's tumour, axillary secondaries. Solitary bone metastasis (incident pain on movement).
Other - e.g. localised breast Ca, rib metastases i.e. unilateral chest wall.
Contact Dr Paul Cook paul.cook@pat.nhs.uk



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Phase III Trial of Prophylactic Irradiation of Tracts (PIT)

Dr Corinne Faivre-Finn and Dr Neil Bayman, Consultant Clinical Oncologists, at The Christie NHS Foundation Trust in Manchester are currently seeking funding to set up a phase III trial of prophylactic irradiation of tracts (PIT) in patients with malignant pleural mesothelioma (MM) following invasive chest wall intervention (for example, CT guided needle biopsy, thoracoscopy, video assisted thoracic surgery or thoracotomy).

The aim of the trial is to establish whether PIT should be offered as a routine treatment to prevent the development of nodules after chest wall intervention in MM in the era of chemotherapy. A national survey conducted in 2007/8 showed that 70% of UK centres are still treating patients with PIT. However only three randomised controlled trials, the largest with 61 patients, have assessed the role of PIT with

conflicting results reported. The Ontario Lung Cancer Disease Site Group (Lung DSG) Guideline Committee published a clinical guideline in 2006 on 'The role of radiation therapy in malignant pleural mesothelioma' based on a systematic review of the evidence. They concluded that the lack of sufficient high-quality evidence precludes recommendations being made on the role of PIT. Importantly, the effectiveness of PIT remains to be determined as does patient benefit in terms of quality of life. In addition the efficacy of PIT, in the new era of palliative chemotherapy is unknown.

The trial design will be a 2-arm, multi-centre randomised trial comparing radiotherapy (21 Gy in 3 fractions) versus no radiotherapy in patients with a diagnosis of MM following chest wall intervention. Patients will be offered chemotherapy (cisplatin or carboplatin and pemetrexed) if deemed suitable by their local oncologist. The results of the trial will also assess the quality of life

and pain scores following treatment with PIT. To date, 28 UK centres have expressed an interest in participating in the trial.

In December 2008 Dr Faivre-Finn submitted a grant application to the Clinical Trials Awards and Advisory Committee (CTAAC) of Cancer Research UK but unfortunately in March 2009 the committee informed the team at The Christie that they were unable to support the proposal. The committee felt that as

70% of centres are routinely using PIT, patients who are randomly assigned to receive no prophylactic radiotherapy on the trial would find this allocation unacceptable. The committee also felt that PIT is considered to be safe and relatively inexpensive, so even if the proposed trial were to add to the evidence against PIT then routine practice would be unlikely to change as a result.

The grant applicants and the trial's protocol

development committee, which include a patient representative, were very disappointed by the feedback from CTAAC and feel that the issues pertaining to mesothelioma research are not being fully understood by the grant awarding bodies. The trial development group feels that the results of the trial are potentially practice changing and have implications for both the NHS in terms of costs and for patient's time and exposure to potentially unnecessary procedures given the conflicting evidence from previous research. Dr Faivre-Finn, Dr Bayman and the trial development committee continue to believe that this is a very important question and are exploring other routes for funding the proposed trial. The team have submitted an application for funding to the joint British Lung Foundation and June Hancock Mesothelioma Research Fund's 2009 research round.

Members of the PIT



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Protocol Development Group:	Cardiff	Hospital, Nottingham	Cancer Nurse
Dr Corinne Faivre-Finn - Clinical Oncologist - The Christie, Manchester	Dr Paul Taylor - Medical Oncologist - University Hospital of South Manchester	Dr John Edwards - Consultant Surgeon - Northern General Hospital, Sheffield	Specialist - The Royal Marsden Hospital
Dr Neil Bayman - Clinical Oncologist - The Christie, Manchester	Dr Mick Peake - Consultant Respiratory Physician - Glenfield Hospital, Leicester	Dr Paul Bishop - Pathologist - University Hospital of South Manchester	Mr David Ardron - Patient Representative
Dr Michael Snee - Clinical Oncologist - St James Hospital, Leeds	Dr Robert Rintoul - Consultant Respiratory Physician - Papworth Hospital, Cambridge	Dr Caroline Lee - Oncologist in training - The Christie, Manchester	Mrs Linda Ashcroft - Senior Statistician - The Christie, Manchester
Dr Jason Lester - Clinical Oncologist - Velindre Hospital,	Dr David Baldwin - Consultant Respiratory Physician - City	Ms Liz Darlison - Consultant Nurse - Mesothelioma UK	Ms Sally Falk - Trial Manager - The Christie, Manchester.
		Ms Sally Moore - Lung	For more information contact: Sally.Falk@christie.nhs.uk

A Breathtaking Journey

1200 miles of breathtaking cycling to highlight the breathtaking scandal of asbestos and breathtaking scandal it has caused. We are cycling through regions of the country that have the highest number of Mesothelioma sufferers.

It is a breathtaking fact that although asbestos is one of the biggest workplace killers, there is almost no dedicated funding for research into cancers caused by asbestos.

Our aim is to raise awareness of the

terrible impact Mesothelioma has upon its victims and their families. We support the campaign for an increase in government funding for research into asbestos related cancers. The breathtaking journey takes place from 20th June - 4th July 2009. Log onto:

<http://breathtakingjourney.blogspot.com/> for up to date details of this journey.

Jason Addy
Katrina London
Paul Glanville -
"breathtaking team"

Coroner Reform Update

See the following link for the third bulletin about the Coroners and Justice Bill's

progress through Parliament for those with an interest in coroner reform:

<http://www.justice.gov.uk/publications/docs/coroner-reform-bulletin-may-2009.pdf>



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June Hancock – A Fight Against Armley's Asbestos

WEST YORKSHIRE
PLAYHOUSE IN
ASSOCIATION WITH I
LOVE WEST LEEDS
FESTIVAL PRESENTS:
DUST
BY KENNETH F YATES
CO-DIRECTORS: ALEX
CHISHOLM, CHRISTOPHER
HILL, MADELEINE
O'REILLY, SOUND
DESIGNER: MIC POOL

I LOVE WEST LEEDS
FESTIVAL: 11 JULY
WEST YORKSHIRE
PLAYHOUSE: 15 - 18
JULY 2009
TICKETS: £9 (CONCS.
AVAILABLE)
PRESS NIGHT:
SATURDAY 11 JULY,
I LOVE WEST LEEDS
FESTIVAL,
REAR OF PET AND
GARDEN WORLD,
LEDGARD WAY,
ARMLEY

In a true story that made legal history in 1997, **West Yorkshire Playhouse** in association with **I Love West Leeds Festival** presents **DUST**, the story of **June Hancock**, a terminally ill cancer patient who won a legal battle against corporate giants T & N, the owners of the J W Roberts Asbestos Factory in Armley, who emitted asbestos fibres

into the area where she lived as a child. Drawn from trial transcripts, interviews and letters, **DUST** is written by local playwright **Kenneth F Yates**, and performed by a community cast members drawn from across Yorkshire. **DUST's** world premiere will be performed in an empty industrial unit close to the site of the original factory at the I Love West Leeds Festival on **Saturday 11 July**, before transferring to the Playhouse's Courtyard Stage from **15 - 18 July**. **DUST** is co-directed by West Yorkshire Playhouse Associate Director (Literary), **Alex Chisholm**, **Christopher Hill** and **Madeleine O'Reilly**.

June Hancock's family moved to Armley in 1936, and June was a pupil at the Armley Board 'Clock' School. The loading bay of the nearby J W Roberts factory was a well known play area for children who lived in the area. Many of them remember moulding the thick, white dust which covered the floor into

snowballs to throw at each other and jumping up and down on sacks of it that were left outside. In 1993, June was diagnosed with mesothelioma, an aggressive form of lung cancer of which the only known cause is exposure to asbestos. June had already experienced the trauma of her mother dying from the same disease, and in 1994, despite having potentially only months to live; she set out on a mission to force the factory to take responsibility for the as yet unknown number of deaths that will be caused by its negligence. Almost three years later, and despite the company's extreme reluctance to produce vital documents, and two separate attempts at appeal, a landmark victory was won against T & N for negligent environmental exposure to asbestos. **DUST** tells the heroic story of June's fight for justice, and of the legal loopholes which mean that many asbestos victims are still waiting for compensation they may not live to see.

Alex Chisholm is West Yorkshire Playhouse's Associate Director (Literary). Her recent productions include the Northern Exposure Double Bill **ME, AS A PENGUIN** and **IT'S A LOVELY DAY TOMORROW**. **DUST** is Kenneth F Yates' first full length play.

All proceeds from the Armley performance of **DUST** will go to **The June Hancock Mesothelioma Research Fund**, a charity which was established by June's family shortly after her death in 1997. The fund supports high quality mesothelioma research projects, contributes to clinical trials and assists with many patient and carer led information seminars and literature. Collections for the fund will take place at all other performances.

The festival is organised by Armley based arts organisation Interplay. The festival director is Jane Earnshaw. Key funding partners in the festival are Arts Council England, West Leeds Area Management Committees, Awards for All, Wades Trust, Tesco and O2. Tickets can be reserved by calling West Yorkshire Playhouse Box Office on 0113 213 7700 or by visiting www.wyp.org.uk



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4th MESOTHELIOMA UK

Patient and Carer Day 2009

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

Saturday 3rd October 2009

Life Conference Centre, Newcastle

The objectives for the day are to give:-

- Mesothelioma patients and carers the chance to meet and share experiences with others affected by the disease
- Up-to-date, unbiased information on the following:-
 - Treatment and Care
 - Clinical Research
 - Peritoneal Mesothelioma
 - Lobbying and Campaigning for Mesothelioma
 - Complementary Therapies
 - Living with Mesothelioma
- Mesothelioma patients and carers the chance to raise issues and ask questions

**For registration details please contact Mesothelioma UK
(details below) or alternatively ask your
local specialist nurse or Asbestos Support Group.**

Mesothelioma UK

National Macmillan Mesothelioma Resource Centre

Helpline: 0800 169 2409

Fax: 0116 2502810

Website: www.mesothelioma.uk.com



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Forthcoming Events

13th World Conference on Lung Cancer
31st July 2009 - 4th August 2009

Venue: San Francisco, USA

Website: www.2009worldlungcancer.org

-----XXXXXXXXXXXXXXXXXXXX-----
European Respiratory Society Annual Congress
12th - 16th September 2009

Venue: Vienna, Austria

Website: <http://dev.ersnet.org/>

-----XXXXXXXXXXXXXXXXXXXX-----
ECCO 15 - 34th ESMO Multidisciplinary Congress
20th - 24th September 2009

Venue: Internationale Congress Centrum, Berlin, Germany

Website: www.ecco-org.eu

-----XXXXXXXXXXXXXXXXXXXX-----
NCRI Cancer Conference
4th - 7th October 2009

Venue: Birmingham, UK

Website: www.ncri.org.uk/ncriconference

-----XXXXXXXXXXXXXXXXXXXX-----
3rd International Cancer Control Congress (ICCC09)
8th - 11th November 2009

Venue: Cernobbio, Como, Italy

Website: <http://www.meet-ics.com/cancercontrol2009/>



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11th Annual National Lung Cancer Forum for Nurses Conference & AGM 2009
19th & 20th November 2009

Venue: Newcastle
Website: www.nlcfn.org.uk

Details to be confirmed – please save the date
NLCFN Members Only

-----XXXXXXXXXXXXXXXXXXXXX-----

8th Annual British Thoracic Oncology Group Meeting 2010
27th January 2010 – 29th January 2010

Venue: To be confirmed – please save the date
Website: www.BTOG.org

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

Mesothelioma UK Contact Details:

☎ Direct Line 0116 256 3739

Fax : 0116 250 2810

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

Helpline: 0800 169 2409

Website: www.mesothelioma.uk.com

Mesothelioma UK Charitable Trust – Registered Charity No 1126083

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.



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