

## Our aims

Encourage and sponsor vital epidemiological research into the causes of mesothelioma

Contribute to clinical trials with novel drug therapies for mesothelioma

Raise awareness of the disease amongst healthcare professionals and the public at large

Provide good quality up to date information and advice for mesothelioma sufferers and their carers

Campaign for delivery of the Mesothelioma Charter

# The June Hancock Mesothelioma Research Fund

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## newsletter September 2008

Proud supporters of the third Mesothelioma UK Patient/Carer Day - 4th October 2008, LEEDS

## The Mesothelioma Charter

We believe people with mesothelioma, and their families, have a right to:

1. A speedy and accurate diagnosis, supported by a Multi Disciplinary Team discussion
2. Good quality information from a variety of sources available in different media and languages
3. Support of a suitably qualified nurse and other Multi Disciplinary Team members throughout their illness
4. Be considered for the best possible treatments available with the support and input of a Multi Disciplinary Team
5. Have up-to-date advice on benefits and help in applying for them, and receive prompt payment of benefits
6. Have legal advice and guidance from a firm of solicitors experienced in mesothelioma claims
7. Guidance on end of life decisions and care at home
8. Provision of a consistent nationwide service from coroners using a clear and open process with a maximum case length of three months

We call upon the Government to:

9. Have mesothelioma made a national priority by the Cancer Tsar
10. Fund good quality research, alongside other national bodies, on mesothelioma with a view to improving diagnosis, treatment and outcomes for patients
11. Support the production of clinical Guidelines on the best practice of diagnosis and management of mesothelioma
12. Ensure the Health and Safety Executive vigorously enforce existing regulations on asbestos

We call upon all employers to:

13. Prevent future exposure to asbestos by providing a safe working environment with all necessary equipment to protect employees
14. Work with unions and individuals to ensure enforcement of current regulations to safeguard all employees
15. Identify all asbestos in their properties and organise its safe removal where practical or necessary when work is being carried out

## Donating Online

Remember it's easier than ever to register your fundraising event online, or to make a donation to someone you know that is registered and raising money for the Fund.

Here's how:

Just Giving – simply log on to [www.justgiving.com](http://www.justgiving.com)

CAF (Charities Aid Foundation) – simply log on to [www.cafonline.org](http://www.cafonline.org)

Donations can be made securely online, which makes this a great way of collecting sponsorship money for your fundraising events. So if you know someone who would like to register his or her event please pass on this information – thank you.

## Donating and Fundraising

You could help us by

- Adopting the Fund as your "Charity of the Year" if you are a business or corporate donor
- Making a Gift Aid or tax efficient donation
- Setting up a monthly direct debit or standing order donation
- Organising your own fundraising event
- Registering your fundraising event on Just Giving [www.justgiving.com](http://www.justgiving.com) or CAF [www.cafonline.org](http://www.cafonline.org)
- Making an endowment or leaving the Fund a legacy

Sponsorship forms can now be downloaded from [www.junehancockfund.org](http://www.junehancockfund.org)

The Fund welcomes all donations large and small to support its work in memory of June Hancock.

[www.junehancockfund.org](http://www.junehancockfund.org)

## Contact Us

If you would like to get in touch, here's how:

Write to us or send donations to:

The June Hancock Mesothelioma Research Fund  
Riverside East  
2 Millsands  
Sheffield  
S3 8DT

Please make cheques or postal orders payable to "The June Hancock Mesothelioma Research Fund".

If you are a UK taxpayer living in this country please include a Gift Aid Form so that the Fund can reclaim the tax. (Gift Aid forms available on request).

Via our website:

[www.junehancockfund.org](http://www.junehancockfund.org)

By telephone:

0114 274 4420

donate

## Action Mesothelioma Day 2008

February 27th marked the third national Action Mesothelioma Day (AMD). Our Fund joined the Ridings Asbestos Support and Awareness Group (RASAG) in hosting an event at Leeds civic hall, attended by well over 80 people. The event was opened by a moving speech from June's son Russell. Other speakers included two mesothelioma patients, RASAG volunteer Ann Lee; Health & Safety Executive regional director David Snowball; Rory O'Neill – Editor, Hazards magazine and international health & safety researcher & campaigner and Macmillan nurse specialist John White.

A highlight of the event was provided by Leeds playwrights Alice Nutter ('Snow in July') and Ken Yates ('Dust') who discussed their plays, and how they came to be written. Ken had also brought along a group of professional actors, who kindly volunteered to perform an extract from his play. The performance was outstanding, and received huge applause. We felt honoured to have hosted such a special performance.

Those attending said the AMD day was very beneficial and informative, and gave an opportunity to hear about asbestos disease and mesothelioma from very many different perspectives. Thank you to everyone who contributed to the success of the day, and of course to everyone who attended.

AMD 2008 raised over £15,000 for the Fund from across the UK, and we wholeheartedly thank everyone who contributed towards that, whether it was helping on the Day, preparing for the Day or whether it was a donation – THANK YOU.

Here's a selection of our wonderful AMD '08 supporters;



### Derbyshire Asbestos Support Team (DAST)

DAST marked Action Mesothelioma Day with a public meeting and balloon release in Market Place, Derby. Over 100 people attended the event to help raise awareness of asbestos exposure and mesothelioma. There was plenty of media interest, which certainly helped get the message across about preventing future exposure to asbestos. The balloons were black, and designed to represent a loved one lost to mesothelioma or someone who was ill with the disease. A staggering £2,343 was raised for the June Hancock Fund.

To contact DAST please call 01623 748161

### Hampshire Asbestos Support and Awareness Group (HASAG)

Sisters Diane McClellan and Lynne Squibb formed HASAG following the death of their father Dave Salisbury from mesothelioma. They dedicate their time helping other sufferers and their families in many ways, including obtaining compensation, home



visits, help with claiming benefits and obtaining good legal advice. They have already raised thousands of pounds for mesothelioma research, and this year held a balloon release in Guildhall Square, Portsmouth to mark Action Mesothelioma Day 2008.

Diane, Lynne and their many helpers raised an amazing £3,000 for the June Hancock Fund. Diane said: "We were delighted to raise so much money for such a good cause, for obvious reasons it is very close to our hearts."

To contact HASAG please call either Lynne 07940 328637 or Diane 07792 543426.

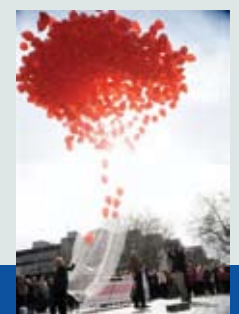


### Greater Manchester Asbestos Victim Support Group (GMAVSG)

On Friday 3rd October 2008 the GMAVSG will be formally presenting a cheque for £6,500 to the June Hancock Fund.

This magnificent donation was raised by hundreds of people in the Greater Manchester area (and beyond!) who sponsored a balloon release in Albert Square on Action Mesothelioma Day 2008.

Those wishing to contact GMAVSG please telephone 0161 636 7555 or go to [www.asbestos-victims-support.org](http://www.asbestos-victims-support.org)



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## June's Fund reaches £1/2 million mark!

*The June Hancock Fund has reached an amazing milestone in its 11 year history – we are delighted to announce that we have now raised in excess of £500,000. This is significantly beyond any expectations we had when we formed the Fund back in 1997. Our target then was £40,000 to help finance a laboratory assistant!*

None of this would have been possible without the many donations, large and small, of all our supporters, and those who have donated to us in memory of a loved one. We thank you all. Sadly, behind many of the donations there is a story of a family losing a relative or friend to mesothelioma. We hope that by having a fund that is entirely committed to mesothelioma research that we are helping something positive to come out of what is a devastating and cruel illness.

*Every penny we receive goes to the Fund.*

## About the Fund and June

Family and friends wishing to carry on June's quest for justice, and to help other sufferers both now and in the future established the June Hancock Mesothelioma Research Fund in 1997 shortly after June's death from mesothelioma.

June's mother, Maie Gelder, also died from mesothelioma in 1982 and it was that double tragedy that led June to seek justice in a test case against the owners of the J W Roberts asbestos factory in Armley, Leeds. They had negligently contaminated their own workforce and the local neighbourhood with deadly asbestos dust. This was described as a true "David and Goliath" battle and against all the odds June won her case and proved that T&N were negligent.

June was 61 years old and her Mum 67 years old when they lost their lives to mesothelioma – exposed as a young innocent family living in the shadow of the factory.

The founders of the June Hancock Fund pledged to continue raising awareness of the disease, helping provide up to date quality information and advice, and to finance independently reviewed specific mesothelioma research projects.

We continue June's battle in her name.

For a full list of our trustees and founders please visit our website [www.junehancockfund.org.uk](http://www.junehancockfund.org.uk)

## Patient and Carer Day Leeds

The third Mesothelioma UK Patient and Carer Day is this year being held in Leeds. It takes place on Saturday 4 October at the Queens Hotel, in the city centre right next to the railway station. Our Fund is proud to be associated with this valuable event, and also to have supported the day by providing a grant.

Registration takes place at 9.45 am, and the day is split in to three sessions with plenty of breaks and refreshments in between. Speakers include John Edwards, Consultant Thoracic Surgeon at the Northern General Hospital Sheffield, Jeremy Steele, Oncology Consultant at St Bart's Hospital London and Chair of Mesothelioma UK, Tony Whitston, Greater Manchester Asbestos Victims Support Group, and Michael Lees, author of the report "Asbestos in Schools". We are pleased to announce that also speaking will be Linda Reinstein, who is the Executive Director and Co-founder of ASAO (Asbestos Disease Awareness Organisation) in America.

Topics include

- treatments for mesothelioma
- clinical research into mesothelioma
- obtaining compensation
- campaigning for mesothelioma
- overview of benefits

Questions and comments from the audience are welcomed, and this provides patients and carers with a unique opportunity to directly address the professionals and experts in their field.

For more information, or to register your attendance please go to [www.mesothelioma.uk.com](http://www.mesothelioma.uk.com) or call the Mesothelioma UK Helpline on 0800 169 2409

Note from the Chair, Kimberley Stubbs:

*"This is a hugely significant milestone, and so I would also like to publicly acknowledge and thank my fellow trustees Adrian Budgen, Vanessa Bridge, Kate Hill, Russell Hancock and Dan Small for their untiring dedication and commitment to the June Hancock Fund. The Fund has come this far in no small part because of them. As a result we are now the only UK registered mesothelioma research charity, and with our research awards and other patient/carer led information projects are actually making a real difference. That makes me very proud indeed."*

## Research Award 2008

The Fund is delighted to announce that we have set aside £120,000 for the 'June Hancock Mesothelioma Research Fund Award 2008'. The grant is available either to medically qualified applicants or to post-doctoral scientists for clinical, laboratory and epidemiological research and palliative care or psycho-social studies in mesothelioma. The research institution must be based in the UK. The closing date was the end of July, so watch this space for more news about the Award or keep visiting our website

[www.junehancockfund.org](http://www.junehancockfund.org)

Anyone in the UK conducting research into mesothelioma is welcome to apply for support from the Fund including doctors, scientists and nurses. We also welcome applications for projects, which directly benefit mesothelioma patients and their carers.

## Research Updates

### Can the body's own defences be used to treat mesothelioma?

In May 2007 Dr Zsuzsanna Tabi was awarded a grant of £138,119 by the June Hancock Mesothelioma Research Fund to find out whether mesothelioma patients' own immune systems can be stimulated to attack the tumour cells. The award runs for three years and the work is being carried out at the University of Cardiff. A post-doctoral fellow: Dr Al-Taei has been employed to work specifically on the project as part of Dr Tabi's team.

Mesothelioma is often diagnosed late when the disease has already progressed. The treatments available at present have limited benefits. This means it is crucial to investigate new therapies which not only help prolong survival and improve quality of life for patients, but may be used to prevent the development of mesothelioma.

The research being done by the Cardiff team uses the fluid which collects around patients' lungs. By studying the cells that are in the fluid it is possible to find out whether the patients' own immune system is able to recognise and attack tumour cells. So far Dr Tabi's team have identified a suitable marker, called an antigen, on the tumour

cells that means it can be recognised by the body's immune cells. This antigen could be used as the basis for a cancer vaccine for mesothelioma.

This could offer a potentially beneficial and non-toxic treatment for patients. In the long term we hope that a cancer vaccine would not only improve the quality of life and survival rate in patients with the disease, but may even be used to prevent the development of mesothelioma in people with known exposure to asbestos.

The June Hancock Mesothelioma Research Fund is pleased to support this important research and wishes good luck to Dr Tabi and Dr Al-Taei in their work over the next two years of the project.

## MARS (Mesothelioma and Radical Surgery) trial

This is a six-year multi-centre randomised controlled trial supported by a grant from the June Hancock Fund. It compares the benefits of extra-pleural pneumonectomy (EPP) versus no EPP i.e. chemotherapy and radiotherapy alone, for mesothelioma patients. By mid April 2008 97 patients had been recruited to the registration phase and 40 have been randomised to the next phase, which is the surgical trial. The trial will produce results in 2011. For more, call the MARS team on 0208 722 4057/4039 or e-mail [mars-icrctsu@icr.ac.uk](mailto:mars-icrctsu@icr.ac.uk)

## Action Mesothelioma Day 2008

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### Sheffield and Rotherham Asbestos Group (SARAG)

SARAG continue to support the June Hancock Fund, and to mark this year's AMD they held events in Doncaster and Rotherham. The Mayor of Doncaster released balloons, and this was followed by the lighting of remembrance candles in memory of those who had died from mesothelioma, or who were suffering from the disease. In Rotherham, friends and relatives of mesothelioma sufferers planted 100 white pansies in the shape of a remembrance ribbon.

These moving events raised £1,250 for the June Hancock Fund.

### Merseyside Asbestos Victims Support Group

Children from Holy Cross School, Fonteney Street, Liverpool together with members and campaigners from the Merseyside and Cheshire Asbestos Victims Support Group released 500 black balloons sponsored by mesothelioma sufferers and their families in aid of the June Hancock Mesothelioma Research Fund. Children were chosen to ensure future generations are made aware of the dangers of exposure to asbestos.

Over 200 people attended the meeting at Liverpool Town Hall (right) where they met civic dignitaries from the Merseyside and Cheshire area. The public meeting called for more funding to find a cure for mesothelioma, and better services for

patients. It also highlighted the 4,000 deaths per year from asbestos related diseases, including 2,000 from mesothelioma. This AMD event raised £1,226.50 for the Fund.

To contact MCAVSG please telephone 0151 236 1895 or go to [www.asbestosdiseases.org.uk](http://www.asbestosdiseases.org.uk)

The trade unions have been very generous and have organised collections for the Fund in previous years – and this year's AMD was no exception. Between them Gordon Glassford, GMB, UCATT, TGWU and AMICUS raised £1,050 which is a wonderful achievement – thank you to everyone involved from the Birmingham, Leicestershire/Midlands and East Coast Region branches.

## research

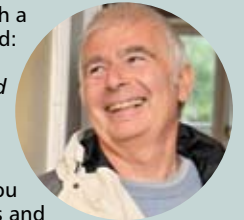
## fundraising

### More fundraising news

Tash Lee's father Ron Lee was diagnosed with mesothelioma in January of this year, aged just 59. Ron doesn't know how he was exposed to asbestos, but thankfully he is responding well to chemotherapy despite having a tough year coming to terms with the disease. Tash decided that she wanted to do something both to raise awareness of the disease and to raise funds for mesothelioma research. So on the 5 July her back garden was officially opened up to 40 friends, family and neighbours for a fun filled day of fundraising. There was freshly

brewed beer available, sideshows and games, followed by an auction in her kitchen of donated goods of every kind. Everyone got into the spirit of things and were very generous with donations and bidding, with a staggering £939 raised. Tash said: "Thanks for all your hard work into researching this hideous and unnecessary disease. Let's hope in the future that fewer & fewer families have to suffer from it."

We say well done and thank you to Tash and all her family, friends and neighbours.



The June Hancock Mesothelioma Research Fund



Carl Ross has taken on a challenge that has been described by many as truly courageous. Sadly, Carl's father Frank died last year 12 months after being diagnosed with mesothelioma. When Carl heard about his friends cycling the "End to End" John O'Groats to Lands End bike ride, he thought he would challenge himself to do it, whilst at the same time raising money in memory of his Dad

for mesothelioma research. The bike ride started on 9th July, and covered 1000 miles in 14 days – we think this is a momentous challenge – well done Carl! (especially considering Carl has never cycled long distance before). Carl is registered on Just Giving, and is donating all proceeds to the June Hancock Fund. Many thanks to Carl and all his supporters, we think this is an amazing feat.

Stuart Smith lives in a small village called Horsford in Norwich, and was diagnosed with mesothelioma in August 2007. In August 2008 Fiona Bradley & Tracy Angel organised a BBQ in their own home to show how much local support there was for Stuart. There were prizes, an auction and tombola and a total of £2000 was raised for the June Hancock Fund to help with ongoing research into mesothelioma.



Janet Booth from Timperley in Cheshire lost her Mum Rita Lea through mesothelioma in 2005. Her good friend Viv had a garden design in mind for the RHS Flower Show held at Tatton. The theme was black & white, to symbolise the link between asbestos & mesothelioma, and was dedicated to Janet's mum. From 1000's of applications to build a 'back to back' garden Vivs design was accepted for one of the 30 plots! A huge achievement – especially with no financial backing and relying only on the generosity & good nature of local business's & close friends. Working 12 hour days & surviving on regular pots of tea and bacon barm the garden took shape and the dream became reality! To everyone's amazement the garden was awarded Silver Gilt, and was featured on BBC Gardeners World. Many visitors to the garden had lost someone through mesothelioma. In total £2250 was raised for the Fund.

Many thanks to all who have helped raise money for the Fund. We wish we could include everyone!

## Karen Wright – welcome to the Team!

Karen Wright is a long time supporter of the Fund. So far this year she has donated over £3,500 through her tireless fundraising, including a charity disco and auction, taking her total donations to well over £13,000. Karen first approached the Fund shortly after the death from mesothelioma of her father Derek Hoult, aged just 64. He had been exposed to asbestos at work. Since then Karen and her family have continued to help raise awareness of the dangers of asbestos.

Clearly Karen has a 'way' with fundraising, and so the trustees of the Fund voted a unanimous "Yes!" when it was proposed that we approach Karen to help our supporters and us in their fundraising efforts. Much to our delight, Karen accepted the position of fundraising advisor, and she is now a fully-fledged member of our team. Karen volunteers her time to help us, and we are immensely grateful – thank you Karen!



"THANK YOU" TO EVERYONE WHO DONATED TO THE JUNE HANCOCK MESOTHELIOMA RESEARCH FUND ON ACTION MESOTHELIOMA DAY

ACTION MESOTHELIOMA