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4th Mesothelioma Patient/Carer Day Saturday 3rd October 2009

Life Conference Centre, Newcastle
This event was kindly supported by a grant from Mick Knighton Mesothelioma Research Fund

The Mesothelioma UK Patient/Carer Day aims to provide up-to-date information relevant to mesothelioma and give attendees the opportunity to meet and talk with national nursing and medical experts and other people affected by the disease in a similar way. This year 100 people attended the meeting.

The day was chaired by John Edwards, Consultant Thoracic Surgeon at Northern General Hospital, Sheffield. The programme for the day included sessions on current treatment patterns for mesothelioma, improving treatment and care in the UK and the role of surgery.

Two patients gave their perspective of living with mesothelioma - Andrew Lawson, a medical ethicist and consultant in pain medicine and Carole Hagedorn, a teacher. Chris Knighton whose husband died of Mesothelioma and set up the mesothelioma research fund in his memory also told her and her husband's story. They were all very honest accounts of their experiences and were truly inspiring.

Attendees were also given information on benefits, legal and compensation issues and complementary therapies. Laurie Kazan-Allen from the International Ban Asbestos

Secretariat covered the global issue of asbestos to highlight that globally asbestos is still being used in domestic and industrial settings.

Natalie Doyle a Nurse Consultant in Rehabilitation at the Royal Marsden Hospital, London closed the day with an excellent inspirational presentation that was littered with really useful practical advice. Natalie used setting up your own business called 'You Ltd' as an analogy for taking and maintaining control once diagnosed with a disease like Mesothelioma.

Feedback from the day has been excellent - here is just a small selection of comments.

"The Q&A bits ere excellent - very informative"

"The question time was most beneficial, allaying fears and concerns"

"Excellent way for patients to network and meet others with Mesothelioma"

"The passion and commitment of everyone was very uplifting. Thank you"

"An amazing day and so well organised. I return home with hope - hope I can sustain it. Thank you"

Thank you to The Mick Knighton Mesothelioma Research Fund and all the supporters of the fund for financially supporting the day.

Dawn Mckinley - Mesothelioma UK Operational Manager

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

Helpline: 0800 169 2409 Fax: 0116 2502810

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

Website: www.mesothelioma.uk.com

MESOTHELIOMA UK CHARITABLE TRUST

An Exciting Opportunity has Arisen for New Trustees

In the UK more than 2,000 people are diagnosed with Mesothelioma each year and this number is increasing. Mesothelioma is caused by exposure to asbestos; the exposure can be quite casual and has usually occurred several decades previously. Mesothelioma is a cancer of the thin membranes that line the inner surface of the chest wall and/or abdomen. It surrounds the organs found within these cavities causing the individual to experience shortness of breath, pain which can be severe, loss of appetite and weight loss and generally results in extreme fatigue and lethargy. For everyone concerned; the patient, family, friends and health care professionals Mesothelioma is perhaps the most challenging of all cancers. Mesothelioma is preventable, difficult to diagnose and treat, debilitating and almost invariably fatal.

The Mesothelioma UK Charitable Trust was set up in late 2008 purposely to raise funds to support the services provided by Mesothelioma UK – this is a free, vital, specialist information, support and educational resource centre.

Mesothelioma UK Charitable Trust needs two further trustees and we would particularly benefit from those with skills in finance/accounting, legal, business, marketing, fundraising or professional background.

The purpose of the role is to work with other Trustees to ensure that Mesothelioma UK Charitable Trust achieves its fundraising objectives and adheres to charitable trust guidelines. Trustees will be required to attend 2 trustee meetings per year and provide comment or advice on an ad hoc basis. Direct involvement with activities would be welcome but is not essential. Trustees' roles are voluntary and unpaid except for expenses incurred in the course of charity business.

We need your help; we hope you never need ours

Please send/email a brief CV and covering letter to:-
The Trustees of Mesothelioma UK Charitable Trust
c/o University Hospitals of Leicester NHS Trust
Hospital Management Offices, Glenfield Hospital
Groby Road Leicester LE3 9QP

Freephone **0800 169 2409**

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

Charitable Trust, registered charity number 1126083

Helpline: 0800 169 2409 Fax: 0116 2502810

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

Website: www.mesothelioma.uk.com

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.

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?page=59>

MESOTHELIOMA UK CHARITABLE TRUST

The Mesothelioma UK Appeal

Mesothelioma UK Charitable Trust will be raising awareness both nationally and locally of the vital service that Mesothelioma UK provides. We are looking for community support throughout the UK as Mesothelioma UK Charitable Trust launches the 'Mesothelioma UK Appeal' in order to generate much needed funds. Every year, it costs thousands of pounds to run Mesothelioma UK and all of our services are **free** to patients, carers and healthcare professionals.

There are many different ways to fundraise and you too can get involved with your family and friends. So for 2010/2011 Mesothelioma UK Charitable Trust is in the process of planning all types of events throughout the calendar year to raise funds which will enable us to continue to fund and support Mesothelioma UK.

We need your help! If you have any ideas on how to raise funds please let us know. Getting involved in a fundraising event is a great way to support Mesothelioma UK; it can be fun and rewarding.

So what will you be doing in the New Year? - Trying to get fit? If so, why not challenge yourself to reach a personal goal and take part in your local or national organised running, walking or cycling event and get family, friends and colleagues to support you, or put on an afternoon Tea Party or Coffee Morning. It doesn't matter how small your event, they all make a difference in both raising awareness and supporting Mesothelioma UK.

We can help you with fundraising materials/packs or just some well placed encouragement! There are hundreds of ideas to fundraise.

There are always updates on our website page in 'Up and Coming Events' and 'Recent Events' for you to read about and maybe inspire you to organise your own event to support Mesothelioma UK Charitable Trust. If you have any fundraising ideas or you would like information on any of our events, or anyone wanting to either take part or volunteer their help, please do not hesitate to get in touch with me as soon as possible. Mesothelioma UK Charitable Trust, would like to thank everybody who has been involved in some way in helping to support Mesothelioma UK so far and look forward to raising funds with you in 2010. **"We cannot do it without you"**. Please contact Jill Lemon on 0116 2563290 or e-mail jill.lemon@uhl-tr.nhs.uk

**Please make it your New Year's Resolution to support
Mesothelioma UK in 2010**

Charitable Trust, registered charity number 1126083

Helpline: 0800 169 2409 Fax: 0116 2502810

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

Website: www.mesothelioma.uk.com

Travel Insurance for Mesothelioma Patients



Patients with Mesothelioma may often find it difficult to get travel insurance as many insurance companies will regard this as a pre existing condition. The Macmillan website has a list of companies that may provide insurance for people with this difficulty.

For the list please go to the link below:

<http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Practicalissues/Travel/Gettingtravelinsurance.aspx>

or go to the following link to order the free Macmillan Booklet

entitled "Getting Travel Insurance when you have been Affected by Cancer"

<http://be.macmillan.org.uk/be/p-87-getting-travel-insurance-when-you-have-been-affected-by-cancer.aspx>

£85m fund set up for soaring asbestos claims

An £85million asbestos compensation fund has been set up in the public sector, amid warnings that medical claims will double in the next decade.

The London Pensions Fund Authority is putting aside the cash following estimates that the number of cases will rise to 25 a year and total more than 400 by 2035.

The organisation deals with about 12 claims a year over asbestos-related illness. But a landmark legal case has led to the authority paying out over a teacher who was not shown to have had direct contact with the substance.

The widower of teacher Joan Henry

who died from mesothelioma - a cancer linked to asbestos - received £180,000 in an out-of-court settlement in July.

Mrs Henry died in 2007 aged 57 after a 30-year career. She had worked in two east London schools whose buildings contained asbestos.

It was the first time the fund, which is responsible for former staff of the Inner London Education Authority and GLC has paid compensation in a case that did not involve a manual labourer who had direct exposure to asbestos.

Mrs Henry's husband Stephen, 59, from Hornchurch, said he

believed the "floodgates" could open for new claims, but feared the fund might have to be even bigger. "I hope that this case will help others receive compensation if they suffer similar tragedies," he said.

"And what about the pupils? Parents need to know their children could be affected by this. Most Inner London Education Authority schools built around the same time had a similar amount of asbestos. Central government knows this stuff is there."

The schools Mrs Henry worked - St Philip Howard in Poplar and Chase Cross in Romford - have both closed.

About 2,100 people are diagnosed with

mesothelioma each year. Lib-Dem MP Paul Rowen carried out research that suggested up to 90 per cent of school buildings still contain asbestos.

A spokesman for Havering council, which employed Mrs Henry, said: "We can't speculate on potential cases in the future."

<http://www.thisislondon.co.uk/standard/article-23761094-pound-85m-fund-set-up-for-soaring-asbestos-claims.do>

Please ask your MPs to sign the following Early Day Motion:

<http://edmi.parliament.uk/EDMi/EDMDetails.aspx?EDMID=39454&SESSION=899>

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Cancer Patients Face Parking Fees

More than half of cancer patients do not get free or discounted parking on hospital visits, contrary to government guidelines, a poll suggests.

The Department of Health has recommended NHS trusts in England offer some kind of concession for people who require repeat visits to hospital.

But the Macmillan Cancer Support survey of 337 patients found most did not.

The NHS Confederation said it planned a charter for hospital parking and said fair charges was the best way forward.

Macmillan Cancer Support said the current situation was unfair and was an "appalling disjointed mess".

Paying for parking is a controversial issue which the charity has long been campaigning on.

Fees are being phased out across the rest of the UK, but in England patients still have to pay.

The poll suggested 59% did not get free or discounted parking - and even among those that did just over a tenth said they did not take it up because it was only offered towards the end of their care.

Mike Hobday, head of policy at Macmillan, said: "The entire hospital parking system is an appalling, disjointed mess, which causes cancer patients unnecessary financial hardship and stress.

"When they are in hospital to get life-saving treatment, vulnerable cancer patients are being hit with this extra and unavoidable cost at a time when they should be focussing on their health.

"Frustratingly, even when hospitals have got concessions in place, they are not telling

patients about them."
'Stressful'

His comments were echoed by Shehnaz Khan, a 52-year-old from Greater London who has been regularly attending hospital since last year for ovarian cancer treatment.

She was only recently told about the discount scheme available.

"Going through treatment is tough enough, but when you're worrying about hospital parking charges too it's so stressful."

A Department of Health spokesperson said: "All trusts should have exemption and concessionary schemes in place to ensure that patients and carers who visit hospital regularly, such as those affected by cancer, are not disadvantaged.

"Trusts are responsible for publicising these schemes to their patients."

Joe Farrington-Douglas, senior policy

manager at the NHS Confederation, which represents trusts, said the organisation was working with hospitals on the issue.

But he added there was a valid reason why hospitals charged for parking. "It is important that funds provided for treatment of patients are not used to subsidise car parking.

"Fair parking charges - properly explained and enforced in an even handed manner, are an important way of ensuring that does not happen."



Contact Albany Lodge on 01202 428151 or go to:

<http://www.albanylodge.co.uk/contact-us.html>

Albany Lodge is owned and operated by the Macmillan Cancer Trust, a local charity based at the Macmillan Unit at Christchurch Hospital in Dorset. The Trust was formed in 1974 to support cancer relief within the East Dorset Health District with the Macmillan Unit, the first in the country and the first to be operated in partnership with the National Health Service, opening in February 1975.

Albany Lodge was the inspiration of the late Charles Hall, the first Secretary of the Trust, who in 1985 sent four patients from the Unit to Swanage for a few days holiday respite during the Summer. On their return the benefits were obvious; the ladies didn't stop talking about the experience for several weeks, so the idea was born. Albany Lodge was purchased in May 1986 and opened in August of that year.

The Hotel has 19 bedrooms, made up of Family, Double, Twin and Single rooms, all with Bathroom En-Suite, with an adjacent Annexe containing a Twin Room and

a newly furnished disabled facility. All rooms contain colour television with remote control, clock radio alarms, and tea and coffee making facilities.

Public rooms include a luxurious Bar Lounge, and another smaller lounge with a large television, CD and DVD player, board games and various reading material. The attractive Restaurant offers good wholesome English food and of course special diets are regularly catered for. There is a large conservatory situated at the front of the hotel.

The hotel has full central heating, private parking, and a small attractive garden for guests to sit in situated at the rear of the hotel. A beach hut is also available for guest's use, which is situated on the sea front within a short walking distance from the hotel. It is a level walk to the cliff top with many benches available to enjoy the outstanding views.

Reservations for the Hotel mainly come as referrals from Hospices, Oncology Departments, GP Practices, Macmillan Nurses, Social Work Departments and other Cancer Care Organisations. Our success has been built on the support of health care professionals,

Macmillan Cancer Support, and of course by word of mouth.

In addition to hotel staff we employ a team of qualified nurse advisers headed by a Nurse Manager, and someone is on call in case of emergency 24 hours a day. We are not allowed to give any "hands on" nursing assistance, but we are able to give back up to the patient if they experience any problems or difficulty during their stay, either by direct contact with their own health care professional or with our local GP Practice. This facility usually gives that bit of extra confidence to the patient who would not consider an ordinary hotel holiday because of their illness or symptoms. We do have a strict criteria that guests have to be able to meet in order for them to enjoy the hotel type of holiday offered.

The hotel operates a strict non-smoking policy within the establishment for the comfort of all guests. A covered open fronted outdoor facility for smokers is available, situated in the rear garden.

Further details are available on request.

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

- 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.

Helpline: 0800 169 2409 Fax: 0116 2502810

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

Website: www.mesothelioma.uk.com

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

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

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