

Mesothelioma UK Newsletter



Christmas Issue - December 2010

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Welcome to our Final Newsletter for 2010

Our patient and carer conference was held on 2nd October in London. Over 200 were registered for the event and feedback has been excellent.

It is difficult to know where to pitch some of the technical presentations, but over all evaluations have been very positive and once again everyone felt very much 'lifted' by Natalie Doyle and her closing presentation.

The 2011 conference will be the first Saturday in October and in response to comments made this year we will be using the same venue.

We were delighted to be able to launch the new patient information package at the conference. Through the Mesothelioma Nurse Action Team we have designed an ideal patient information pathway and written numerous booklets to complement it. We have since launched the pathway to lung cancer nurses where it has been very well received and orders for copies have been coming in thick and fast.

Thank you to Gerry Slade for working so hard with me and the members of M-NAT to get the pathway developed. The full pathway should be uploaded onto the National Information Pathways website shortly.

The second Mesothelioma Practice in Cancer Care On-line module starts on 24th January. Anyone interested in applying should contact the Royal Marsden School of Cancer Nursing and Rehabilitation Tel: 020 7808 2900 Email: school@rmh.nhs.uk

I can hardly believe I am writing this, the months have gone by so quickly, but all of us at Mesothelioma UK hope you have a very enjoyable festive holiday and sincere best wishes for 2011.

Liz Darlison
Nurse Consultant

**If you have an event you
would like to publicise or you would
like to write an article for a future
newsletter please contact
mesothelioma.uk@uhl-tr.nhs.uk**



MESOTHELIOMA UK

MALCS - Mesothelioma And Lung Cancer Study (An NCRN Postal Survey – NCRN ID 1167)

MALCS was set up over 10 years ago to estimate the mesothelioma and lung cancer risks associated with specific occupations across Britain.

Although we have moved office, nothing else about MALCS has changed and we are still open to recruitment until 2015. Britain has the highest mesothelioma rate worldwide, and the rate is still increasing 25 years after asbestos use virtually ceased. We need to continue recruiting patients into MALCS to evaluate potential risks to younger workers in various occupations.

Please notify the MALCS study team of the following patients:

- Male mesothelioma patients born since 1940
- Male primary lung cancer patients born since 1940 who have had ANY surgery to remove lung tissue over and above a biopsy
- Female mesothelioma patients born since 1925

We are still open for recruitment. Please continue to help us. Boost your NCRN funding with this easy postal survey – you identify the patients and we send out the survey – it really is that simple

How to recruit patients:

1. Give the patient a patient information sheet and complete a 1-page notification form
2. Send the notification form to us at the London School of Hygiene & Tropical Medicine

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 in London.

NCRN funding is awarded for every patient notified to us in this way (irrespective of whether they subsequently take part by returning the postal survey we send them).

For further information, please contact the MALCS study team:

Telephone: 020 7927 2860 or
E-mail: MALCS@lshtm.ac.uk

Cancer Research UK Epidemiology & Genetics Unit
Department of Non-Communicable Disease Epidemiology
Faculty of Epidemiology & Population Health
London School of Hygiene & Tropical Medicine
Keppel Street
London WC1E 7HT

Travel Grants

The June Hancock Mesothelioma Research Fund are pleased to announce that they are now awarding up to 10 travel grants a year.

Applications will be considered from researchers and health care professionals to support travel to conferences where applicants will either present papers or speak to a poster exhibit.

In certain circumstances grants may also be awarded for educational purposes, for example, for a study visit to an academic centre or to attend a course. Applications for co-sponsorship with other organisations or institutions are welcome.

Individuals may apply for up to a maximum of £500.00 in any one year period.

Applications should be made in advance of the proposed travel to permit a decision to be taken before any expense is incurred. Successful applicants are required to complete and return a claim form no later than one month after the travel date with details of the actual costs incurred. Applications to support conference presentations must include a copy of the submitted abstract.

To apply for a travel grant you will need to complete an application form. These can be obtained from the JHMRF by contacting Dr Kate Hill by email k.m.hill@leeds.ac.uk or telephone 0113 343 0864.

Travel Insurance



Patients with Mesothelioma or other types of cancer may often find it difficult to get travel insurance as many insurance companies will regard this as a pre existing condition. Mesothelioma UK can provide a travel pack listing companies who may be willing to insure these patients.

To obtain a travel pack please call 0800 169 2409 or email mesothelioma.uk@uhl-tr.nhs.uk

The Importance of Patient Support Groups

Mesothelioma support groups are an invaluable help to patients and their carers but access to them is limited.

Much is done to address the physical symptoms of mesothelioma for example breathlessness, pain, tiredness, loss of appetite, weight loss etc. but there is one aspect of the disease that is less talked about - the psychological impact of the disease on the patient and their carers. A British Lung Foundation Survey of mesothelioma patients and their carers in February 2009 showed that 79% of carers and 41% of patients felt isolated or alone some or most of the time.

Two years ago at Papworth Hospital in Cambridge a specialist nurse, at the request of a patient, set up a mesothelioma support group. The group has grown and now attracts an average attendance of twenty-seven patients and their carers. Many patients are prepared to travel from outside the area – in some cases involving a round trip of up to seventy miles. This shows how much they value the psychological benefit they get from meeting fellow sufferers, exchanging ideas and giving and receiving mutual support.

The gatherings are far from sober occasions. There is much laughter with frequent requests to keep the noise down by directors and administrators in adjacent rooms. Recent meetings have included talks on pain control, breathlessness, diet and exercise. These are followed by refreshments and a weekly raffle.

In early 2009 a separate, carers only group was formed. In this forum carers are able to address the concerns that are sometimes difficult to discuss in front of the sufferers. Over time close friendships have been formed and the mutual support continues after bereavement. For the healthcare professionals involved with the group, it has provided a very informative insight into the problems, concerns and interests of patients and their carers.

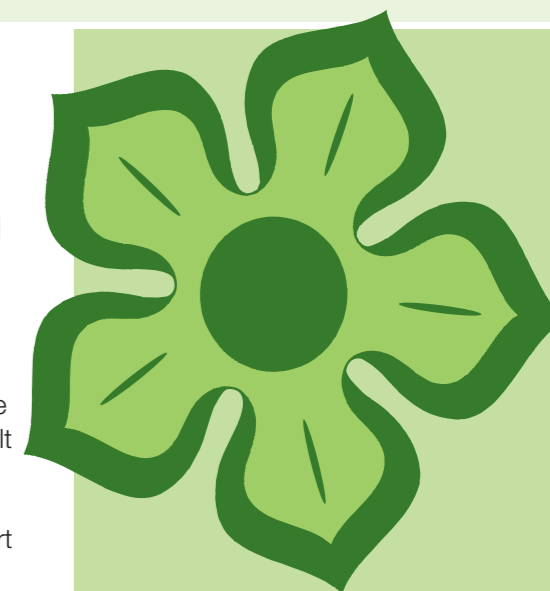
The enthusiasm is infectious and recent fundraising by the group has raised over £2000 for research and education. A website has been designed to enable patients and their families to access up to date information on meetings with the newest innovation being an internet forum where they can exchange views and comments.

I hope the positive experience of our mesothelioma support group will encourage and empower patients, carers and healthcare professionals to set up similar groups around the country.

<http://www.papworthhospital.nhs.uk/mesosupportgroup>

by Gerry Slade
Mesothelioma Lung CNS

See back page to find your local patient support group.



Forthcoming Events for Health Professionals

British Thoracic Society Winter Meeting 2010
1st Dec 2010 to 3rd Dec 2010
Queen Elizabeth II Conference Centre, London
www.brit-thoracic.org.uk

12th Central European Lung Cancer Conference (CELCC12)
2nd Dec 2010 to 4th Dec 2010
Budapest, Hungary
www.celcc2010-budapest.hu/

Chicago Multidisciplinary Symposium in Thoracic Oncology - American Society for Radiation Oncology - Co-sponsored by ASCO, ASTRO, IASLC and University of Chicago
9th to 11th Dec 2010
Chicago, Illinois, USA
www.thoracicsymposium.org/

9th Annual British Thoracic Oncology Group Conference 2011
Wednesday 26th to Friday 28th
January 2011 at
The Burlington Hotel, Dublin, Ireland
www.btog.org

BTOG / Mesothelioma UK
Postgraduate Course in
Mesothelioma and BTOG
Postgraduate Course in Lung Cancer
28th to 30th Mar 2011
Glenfield Hospital, Leicester
Email dawn.mckinley@uhl-tr.nhs.uk

**To order patient information
booklets please call our freephone helpline on
0800 169 2409
or email
mesothelioma.uk@uhl-tr.nhs.uk**

Mesothelioma – A Patient’s Story

I never actually worked with Asbestos...all this pain and despair for me was caused by washing my husband’s clothes back in 1961.

After National Service he went back as a Shipwright in the Dockyard where he worked with asbestos. We married and he left to work at British Uralite making Window Boxes for Council flats etc.

Ray had a scan and he has scarring. I, on the other hand, have Mesothelioma. I washed his clothes.

Prior to my diagnosis I was a very active person. I regularly went to keep fit classes, went swimming, walked in the countryside - 14 miles sometimes and every day without fail walked the dog 2.5 miles. This changed on coming back from holiday in Spain in 2009.

I had burnt myself on an iron over the new year and had not felt it. My arms and hands twisted and my feet went numb and I couldn’t breathe. A visit to the doctor resulted in an admission to K&CC hospital. They drained 5 litres of fluid from my lungs. I was given the news that I had Mesothelioma and no future, such a pretty name for a deadly disease. Prognosis was 3 months to 2 years .

I arranged my funeral, threw out my old clothes and bought new things for the home so that Ray wouldn’t have to worry about such things.

I was given an appointment for Mrs King and she carried out the Talc op in Guys Hospital. The operation was a success and this was followed by wound radiation and chemotherapy. I hated the chemo - 10 hours of watching fluids going into my veins and then next day sick. I was so weak that I needed a stick to hold me up when I walked around.

Just as I got better the next 21 days came round and another chemo and back to the sickness and weakness. But after 4 sessions the CT scan showed I was stable. I enjoy life again and I’m able to walk the dog, but I do tire easily and afternoons I drop off to sleep. I now have a tumour that is shrinking but we don’t know when it will return.

We have a motor home and during the past 4 months we have covered just over 4 thousand miles travelling around the UK.

We recently had the results of my latest scan. The Oncologist said “we don’t often sit in this chair and give out good news but today is an exception”. He handed me the results and said “your tumour has shrunk”.

I said “I didn’t think that was an option”. “Well it’s true and you can read the report”. But as I looked at Ray who was staring at the doctor I could see his jaw drop and his mouth was open but he wasn’t saying anything. The Doctor was so excited at my news he kept shaking my hand. I asked him what this means for me now. I had a 3 month timescale, which was now at a year. “So how long now?”. He stretched his arms wide open “who knows” he said “you are unusual and lucky to get this news. Your prognosis is an open ended situation”.

I get very tired now and my husband tells me to rest and slow down, but this illness is terminal and it’s not going away. I need to do all the things that I’m able to while I can. It wont beat ME I will beat IT. Mesothelioma didn’t know what it took on when it started on me!

By Mavis Nye (See Ray and Mavis’ Blog: <http://rayandmave.co.uk/default.aspx>)



MesoVATS Trial

Prospective randomised controlled trial of VAT cytoreductive pleurectomy compared to talc pleurodesis in patients with proven or suspected malignant mesothelioma.

In the last 12 month period (September 2009 – October 2010) we recruited 49 patients. Therefore, we achieved our target of 4 patients a month. All this is due to a lot of hard work by you all. Many thanks.

We are pleased to report that two new surgical centres have recently opened – New Cross Hospital in Wolverhampton (Local PI Mr Ian Morgan) and Leeds Teaching Hospitals NHS Trust (Local PI Mr Nilanjan Chaudhuri). In addition, three centres (Harefield Hospital, St Georges Hospital and Colchester General Hospital) are going through the R&D approvals system. Once they are opened we will have a total of 11 surgical centres and 4 non-surgical centres. We look forward to them all being up and running soon.

The Trial Steering Committee recently decided to have all the initial staging CTs read by a pair of radiologists so that we can compare the radiological staging of all patients in each arm. To do this we are submitting a protocol amendment so that we can request copies of the CTs from each hospital.

Many thanks to all of you who have recruited recently – let’s keep going! We urge you all to have one last big push. If every site could recruit 3 more patients we will get there!

Recruitment Update

To date 154 patients have been recruited and randomised out of a target number of 196. We are now over 75% of the way!

Basildon 14, Sheffield 34, Leicester 12, Guys 6, Papworth 85, Brompton 1, Nottingham 2

Helen Munday
Papworth Hospital NHS Trust
helen.munday@papworth.nhs.uk

The Delivery of Coroner Reform

On 14 October 2010, Jonathan Djanogly MP, Parliamentary Under-Secretary of State at the Ministry of Justice, made a written statement to Parliament announcing plans for changes to the coroner system in England and Wales.

This followed an internal review of the scope and timing of coroner reform in light of the difficult financial situation facing Government as a whole.

In a statement, the Minister stressed: “We believe the proposals I am putting forward today will bring improvements to the system, and address current inconsistencies and inefficiencies in the delivery of service to bereaved families”

It is intended to bring forward a number of measures from the 2009 Act to achieve these aims, including:

- enabling operational problems facing coroners to be addressed;
- reviewing and updating the Coroners Rules;
- issuing and monitoring guidance on compliance with best practice, including a new national charter for bereaved people;
- maintaining and improving training for coroners and their officers, and
- encouraging the further establishment of support services provided by the voluntary sector to those attending.

We believe that this package, underpinned by suitable guidance, will deliver real and significant improvement to the way in which the coroner service is delivered. The Minister recently met with a number of civil society groups, including the British Lung Foundation (BLF), to discuss how best to take forward reform and we are aware of the work carried out to date by the BLF with the Coroners’ Society to create best practice guidance for coroners on mesothelioma. Ministers are keen to build on this collaborative approach to ensure that we are able to deliver their aims for the coroner system.

Please e-mail coronersandburials@justice.gsi.gov.uk

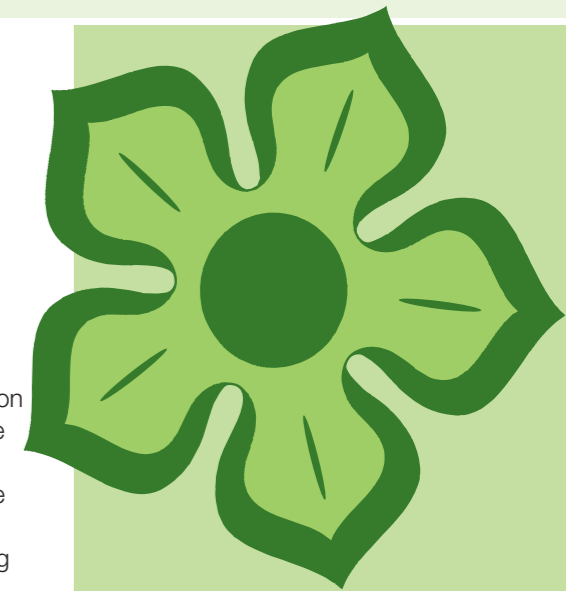
Elizabeth Gibby Deputy Director responsible for Coroners, Burials and Legal Services Regulation and Redress, Ministry of Justice

In line with this, we will be consulting on a revised Charter for Bereaved People in light of the recent announcement. The Charter will make a real difference to families and we are keen to work with all interested parties in developing a draft.

The current financial situation does mean that these reforms must be brought forward without the national leadership framework and new appeals system, headed by a Chief Coroner. In order to achieve improvements and benefits for the bereaved, some of the functions of the Office of the Chief Coroner need to be transferred to an alternative body. To enable the transfer of functions, the Office of the Chief Coroner has to be abolished, and it has been proposed that this will be done alongside the abolition of other public bodies in the Public Bodies Bill.

The Health Secretary’s decision to take forward the introduction of medical examiners – to work in parallel with coroners to ensure that poor or criminal certifying practices are detected and addressed – will be a significant improvement. As a secondary purpose, it should enhance the medical knowledge available for coroners to draw on when investigating their own cases. Jonathan Djanogly’s statement sets out other changes we are intending to take forward – it can be accessed at www.justice.gov.uk/consultations/reform-coroner-system.htm.

The Government is committed to reforming the coroner system and we believe that the proposals outlined will provide for significant improvement. However, as outlined, we continue to welcome interaction with all with and would be keen to hear your views.



Mesothelioma UK Patient Information

Mesothelioma UK and the Mesothelioma Nurse Action Team recently produced a range of patient information booklets including:

“What is Mesothelioma?”

“Concerned About Asbestos Exposure?”

“Asbestos and the Diseases it Causes”

“Radiotherapy and Mesothelioma”

“Surgery for Malignant Mesothelioma”

“Mesothelioma Support” and various others.

We have had quite a lot of interest in these booklets. To find out more about them and to order copies please call freephone no. 0800 169 2409.

Alternatively, an order form is available on our website www.mesothelioma.uk.com

Please complete and post to address on form or email mesothelioma.uk@uhl-tr.nhs.uk with your order.

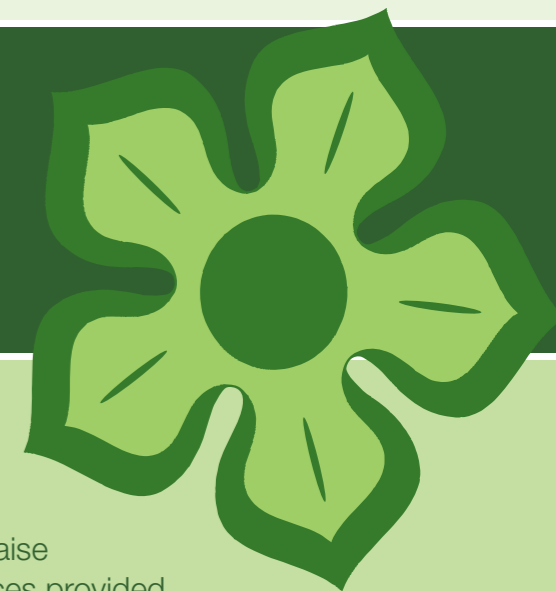
**Tracey Heseltine
Mesothelioma UK**

Mesothelioma UK Charitable Trust 1126083

Fundraising News

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- Fundraising News
- Patient & Carer Day
- The Festive Season



Support Mesothelioma UK Charitable Trust for:

A Month ~ £14,166
 A Week ~ £3,720
 A Day ~ £675.00
 An Hour ~ £85.00

Contact:

Jill Lemon Mesothelioma Fundraising & Marketing Manager
 jill.lemon@uhl-tr.nhs.uk

Mesothelioma UK

Freephone: 0800 169 2409
 www.mesothelioma.uk.com

If you want to sponsor any of our fundraisers, go to our website and click on the links.

Log on to www.mesothelioma.uk.com and "Buy a minute for a pound". We thank you for your support. Every little helps.

Do Something Good Today support Mesothelioma UK

On behalf of the Charitable Trust, I would like to thank all those, including our corporate friends who have contributed, supported and sponsored Mesothelioma UK during 2009-2010.

I would like to wish you all a very merry Christmas and a Happy New Year.

Jill Lemon
 Fundraising Manager

Fundraising

To celebrate your fundraising achievements, on the Mesothelioma UK stand at the patient and carer day, we had an overview of the year's fundraising trials and tribulations.

They included pictures and stories of trekkers who scaled Kilimanjaro, skydivers throwing themselves out of planes, bikers who have cycled from one end of the country to the other, walkers, runners, Tombolas, fetes, cake sales, concerts, both rock and choral and last, but not least, quiz nights to mention but a few. All these events have raised awareness throughout the country as well as much needed funds enabling Mesothelioma UK to continue their vital work.

We have been better able to support you with your fundraising initiatives with our new fundraising packs, which include leaflets, t-shirts, running vests, water bottles, pins, table cloths, banners, pens and balloons and we hope to continue expanding.

Our aim is to raise the funds necessary to sustain Mesothelioma UK which requires:- £170,000 per year

Details of all sponsorship, donations, fundraising and successful grant applications are posted on our website www.mesothelioma.uk.com

The Mesothelioma UK Pedometer Challenge

The Pedometer Challenge was met with oodles of enthusiasm and we have had many people sign up in a bid to raise their fitness levels as well as funds. The Pedometer Challenge will be ongoing, so if you would like your pedometer pack please ring freephone 0800 169 2409 and order yours.

Information about the challenge and how it helps to support Mesothelioma UK can be found on the website or ring 0800 169 2409.

The Patient and Carer Day

I met a number of wonderful people at the Patient and Carer conference.

Their inspirational fundraising activities have been a phenomenal success for our first charitable year and we hope that as the charity progresses we can begin to build on our own activities.

We were able to roll out the new Mesothelioma UK Patient Information Leaflets at the conference that the Mesothelioma Nurse Action Team (MNAT) worked very hard together to produce and which the Charitable Trust were able to fund due to your support.

I would like to thank Clive and Gill Leaney for their support on the day, by distributing leaflets and pins, and encouraging people to take up the Pedometer Challenge.

The Festive Season

Christmas is nearly upon us and we will be holding our annual Tombola stall at the Glenfield Hospital main reception on the 7th December.

Come along and support us, or if you would like to take a turn and help on the day please contact us on 0800 169 2409.

The festive season is a time when people get together, and begin to think of family, friends and loved ones who may no longer be with us or who are living with mesothelioma. You may decide you would like to honour a day during December in celebration, or in memory of their life. Throughout December Mesothelioma UK are offering celebration memory days for £10.00 on the Mesothelioma UK Charitable Trust website.

The Charitable Trust has Christmas Cards in stock. Order yours today, 2 designs in a pack of 10 @ £4.00 per pack.



2010 Sponsors

The Mesothelioma UK Charitable Trust exists to raise funds to support the services provided by Mesothelioma UK and any sponsorship, grants or donations made to the charity support this. To run Mesothelioma UK for 1 year **£170,000** is required.

With grateful thanks to our sponsors for 2010



The Mick Knighton Mesothelioma Research Fund has kindly provided a grant of £49,660 to fund the Mesothelioma UK Helpline for one year.

Gold Sponsors



Eli Lilly and Company Limited

Silver Sponsors



Anthony Coombs



FIELD FISHER WATERHOUSE

Building & Civil Engineering Charitable Trust



Pierre Fabre

Bronze Sponsors



Rocketmedical

UK MEDICAL

Mesothelioma Patient Support Groups

Barrow Asbestos Related Disease Support (BARDS)

Tel: 01229 580305 or 01229 430111

For patients with asbestos related disease, their families and carers

East & North Hertfordshire Lung Cancer/Mesothelioma Support Group

Contact Patricia Swann 01707 328111 Ext: 3319 Elaine Dockree 01438 781217

Provides support to patients/carers

East London Mesothelioma Support (ELMS)

Freephone Helpline: 0800 8766773 Between 5pm-10pm

Support, guidance and information for patients, carers, relatives, friends

East Midlands Mesothelioma Support Group (EMMSG)

Contact Mesothelioma UK on freephone 0800 169 2409

For those in East Midlands with mesothelioma and their families/carers

Hampshire Asbestos Support & Awareness Group (HASAG)

Contact Lynne on 07940 328637 or Diane on 07792 543426

For sufferers/families of those with all asbestos related diseases including the bereaved

Hands of Time Mesothelioma Support Group

Contact Dimbleby Cancer Care on 0207 1885918

For patients/carers

Leeds Lung Cancer & Mesothelioma Patient Support (LAMPS) Support Group

Contact John White on 0113 2067916

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

For Lung Cancer/ Mesothelioma patients /carers

Mesothelioma Self Help Group

Tel: 0191 263 7386 (Mick Knighton Mesothelioma Research Fund)

Aims to provide information and support to sufferers and their families

Mesothelioma Support Group at Guy's Hospital, London

Contact Rachel Thomas 020 7188 4758

Mesothelioma Support Group at Royal Marsden Hospital, Surrey

Contact Natalie Doyle on 0207 352 8171 Ext: 1791 or Sonja Watson on 020 8661 3150

Mesothelioma Support Group at Papworth Hospital, Cambridge

Contact Gerry Slade, Mesothelioma Specialist Nurse on 01480 830541 Ext: 4889

For patients/carers

Swindon & South West Support Groups

Contact Mrs Pat Lewis on 01793 532995

Group for widows/partners of asbestos sufferers

Contact Janice Howell on 01793 813616

Group for patients and their partners

Contact Maureen Seabrook on 01822 880233

Wives & Widows Group

Southend Lung Cancer and Mesothelioma Support Group

Contact no 01702 435555 Ext: 6835

Canvey,Basildon and Thurrock Lung Cancer and Mesothelioma Support Group

Contact No: 0845 155 3111 Ext: 3168

Email:

Jolly.barber@southend.nhs.uk, Johanna.phelps@southend.nhs.uk or Michelle.palmer@southend.nhs.uk

West Hertfordshire Trust Support Group

Contact Linda Charalambous on 01923 21701

For all West Hertfordshire Trust lung cancer/mesothelioma pts

Wigan and area Lung Cancer /Mesothelioma Support Group

Contact Venencia Sibanda, lung cancer specialist nurse, on 01942 822260

For lung cancer and mesothelioma patients