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Mesothelioma UK Update

Dear Reader

Welcome to this latest edition of the Mesothelioma UK Bulletin.

The work of the Resource centre continues to grow and we have been as busy as ever. We held our 4th Patient and Carer Conference on Saturday October 3rd in Newcastle. The event was kindly sponsored by the Mick Knighton Mesothelioma Research Fund and it was attended by 100 people. Evaluations received were excellent and we will endeavour to build on this success in the future. Suggestions for the 2010 venue are Royal Tunbridge Wells, Birmingham and London. Let us know your thoughts. A big thank you to all

those who attended and to the speakers for giving excellent presentations. Obviously a huge thank you to the MKMRF for their presence and financial support.

Website and Helpline:

In the last quarter Mesothelioma UK has received 226 contacts via the helpline or email and there have been 803 hits on the website.

M-NAT: The next Mesothelioma Nurse Action Team meeting will be held in London on 6th November where the nurses in attendance will have the opportunity to discuss and learn about setting up a tunneled drain service, chemotherapy, trials and hearing about a patient's own personal experience.

N-CARD: The National Centre for Asbestos Related Diseases initiative is making progress. There is genuine interest in the concept within central government and the Working Group is currently preparing a strategy document to outline the purpose, priorities and possible funding and infrastructure for the centre. Watch this space!!!

Priorities for us over the next few months will focus on fundraising to ensure the viability of Mesothelioma UK and we have already approached a variety of funding sources for support. Any ideas on this front will be gratefully received. Thank you for your continued support.

Liz Darlison



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



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The Mesothelioma UK Appeal

I joined Mesothelioma UK Charitable Trust as Fundraising Manager in July 2009. "Every year, it costs £170,000.00 to run Mesothelioma UK and all of our services are **free** to patients, carers and healthcare professionals. The Charitable Trust is going to 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. We are in the process of revamping our website and developing a range of written patient information materials and we would ask that in your local area please raise awareness about our service and ensure all your mesothelioma patients and carers know about us.

If you have a mesothelioma support group in your area you may want to encourage them to log on to our website and request our bi-monthly news letter or hold local fundraising events. If so just point them in our direction where we will be able to help with fundraising materials/packs or just some well placed encouragement! There are hundreds of ideas to fundraise.

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

Thank You.

Jill Lemon, Fundraising Manager Mesothelioma UK Charitable Trust.



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New Test for Mesothelioma

Scientists may have developed "a more sensitive test for the asbestos-related cancer mesothelioma", according to a story in BBC News. This devastating cancer is usually diagnosed by looking for cancerous cells in the fluid surrounding the lungs (cytology), but this method is not a very sensitive test and does not distinguish well between mesothelioma and other cancers. See [BBC News' article on the new test for](#)

[mesothelioma.](#)

In a well-conducted [diagnostic study](#), researchers in Oxford assessed the accuracy of combining cytology with their new test, which measures the amount of the protein mesothelin in fluid around the lungs. They demonstrated that this is a valuable addition to the usual cytology tests given to people with possible mesothelioma.

Importantly, the researchers suggest

that this test should be used alongside cytology, although it also performed well alone. This potential new method has the benefit of being performed on the same fluid samples currently used in diagnosis by cytology, so it could easily be added to current testing programmes. Go to following link for full article:

<http://www.nhs.uk/news/2009/08August/Pages/MesotheliomaAsbestosTest.aspx>

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/Get_Support/Getting_travel_insurance/Travel_insurance_companies.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>



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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."



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Asbestos in Schools Update - October 2009

Much has happened in the asbestos in schools campaign since the last article in the Mesothelioma UK newsletter, however as with most things concerning asbestos, it is a long hard battle. The issue has been raised at the highest level politically, and there is increasing public awareness because of widespread press interest with both local and national coverage. The campaign is now under the auspices of the All Party Parliamentary Group on Safety and Health and supported by the six teaching unions, MPs, the three support staff unions, health and safety professionals, asbestos consultants, members of the medical profession and legal profession, parents, teachers, school staff and others united in the aim of making schools safe from the dangers of asbestos.

In March there was a Parliamentary debate on Asbestos in schools which was led by Paul Rowen MP and answered by the DCSF Minister Sarah McCarthy-Fry. The Minister highlighted the need for training and emphasised that asbestos

will normally be removed from secondary schools during major refurbishments under the Building Schools for the Future initiative, but did not mention the policy for primary schools.

In May a delegation from the campaign met the Prime Minister and requested that his Government should assess the extent of asbestos in schools, carry out a risk assessment with special emphasis on children, train people and reinstate the campaign to improve asbestos management in schools. He was also asked to adopt a policy of removing asbestos when schools are refurbished with the ultimate goal of removing all asbestos from schools. He acknowledged that there is a serious problem of asbestos in schools and that it is one that has to be addressed. So that could be achieved he asked his Minister to arrange a meeting.

The meeting with the Minister took place in June where regrettably the impression was given that despite the Prime Minister's instructions, she and her Department seemed content with their present policies and that

the status quo would be maintained. The Minister emphasised that although Government policy was normally to remove asbestos during secondary school refurbishments, there is insufficient central or local funding to remove, or even identify asbestos during primary school refurbishment.

In July the Chief Executive of the British Safety Council gave a speech at a conference on Corporate manslaughter and health and safety enforcement where he said *"It is unacceptable that the UK, in 2009, has not yet undertaken a national audit of asbestos in schools; has not comprehensively assessed the risks that teachers and pupils in each and every school face; and has not allocated resources to take urgent remedial actions."*

Without these actions the tragedy of asbestos in schools will be left to fester and continue to kill the lifeblood of our society. Teachers and pupils continue to live with the deadly legacy of having once worked or studied in a school containing asbestos."

In September a strong delegation from the campaign held a meeting with senior HSE officials, where although they announced some minor changes the HSE would not accept that there is a serious asbestos problem in schools and that their policies are not working.

The year began with great hopes that there would be a step change in Government policy, however our request to undertake the most basic first steps in risk management have been refused - the reason being that the Government are afraid if they took that step then it would open a Pandora's box. So the asbestos incidents in schools continue unabated, contaminating the schools and exposing the teachers, support staff and children. Sadly the end result is that the cases of mesothelioma amongst people who were exposed to asbestos at school continue to increase. The campaign will succeed, it is just so sad that when it does it will be too late for some.

By Michael Lees
10th October 2009



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MesoVATs Trial

The MesoVATs trial is a randomised controlled trial of VAT pleurectomy versus talc pleurodesis for patients with confirmed or suspected malignant mesothelioma.

Recruitment has markedly improved over the last year and we currently have a total of 108 patients randomised out of a target of 196. The improvement in recruitment rate is due to now having 5 surgical centres recruiting along with their feeder hospitals. The current surgical centres are Northern General Hospital, Sheffield; Glenfield Hospital, Leicester; Basildon Cardiothoracic Centre, Guy's Hospital, London and Papworth Hospital, Cambridge.

Furthermore, we are discussing opening of the study with two further surgical centres. Earlier this year, we reviewed the overall progress of the trial and the protocol. Some amendments have been made to the study protocol which

appear to be facilitating recruitment especially for patients entering the study in the 'suspected mesothelioma' arm.

We have set ourselves the target of completing the study in the next 2 years and to do this we need to recruit 50 patients per annum. This equates to 10 patients for each surgical centre, a target which we believe should be achievable given the volume of cases seen in each centre.

Following the closure of MARS, MesoVATs is currently the only active randomised trial for Mesothelioma in the UK. It is an important study to complete and we would ask for you to consider it for patients presenting with confirmed/suspected mesothelioma who have a pleural effusion. The study is NCRN approved and in the NIHR trials portfolio. If you do have a patient who you would like to be considered

for the study please contact one of the PIs listed below who will be able to see your patient and consider them for eligibility.

Papworth Hospital

Dr Robert Rintoul
robert.rintoul@papworth.nhs.uk

Basildon Cardiothoracic Centre

Mr Andrew Ritchie
andrew.ritchie@btuh.nhs.uk

Guy's Hospital

Mr Loic Lang-Lazdunski
loic.lang-lazdunski@gstt.nhs.uk

Northern General Hospital, Sheffield

Mr John Edwards
john.edwards@sth.nhs.uk

Glenfield Hospital, Leicester

Mr David Waller
david.waller@uhl-tr.nhs.uk

by Dr Robert Rintoul

robert.rintoul@papworth.nhs.uk



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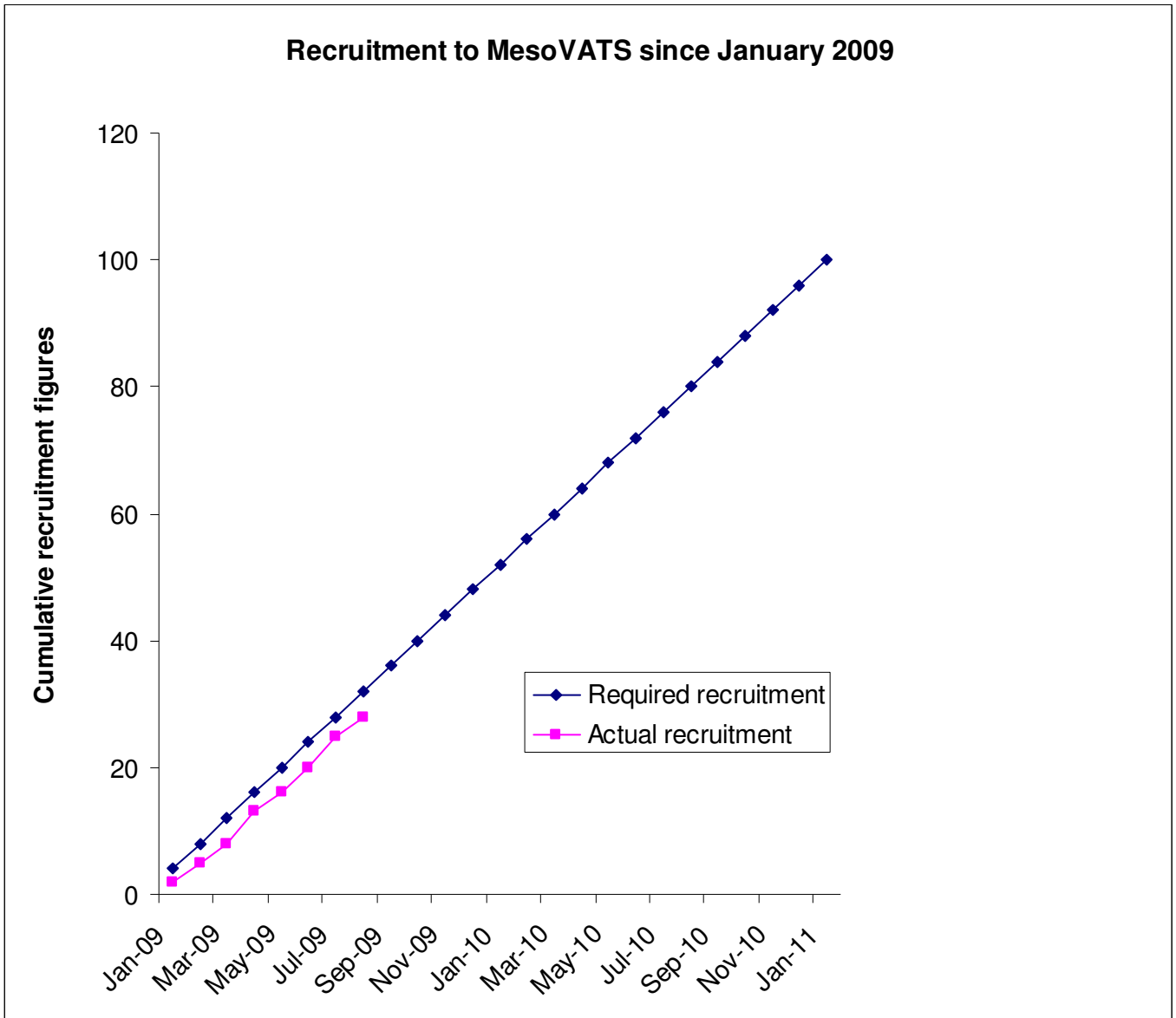
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MALCS

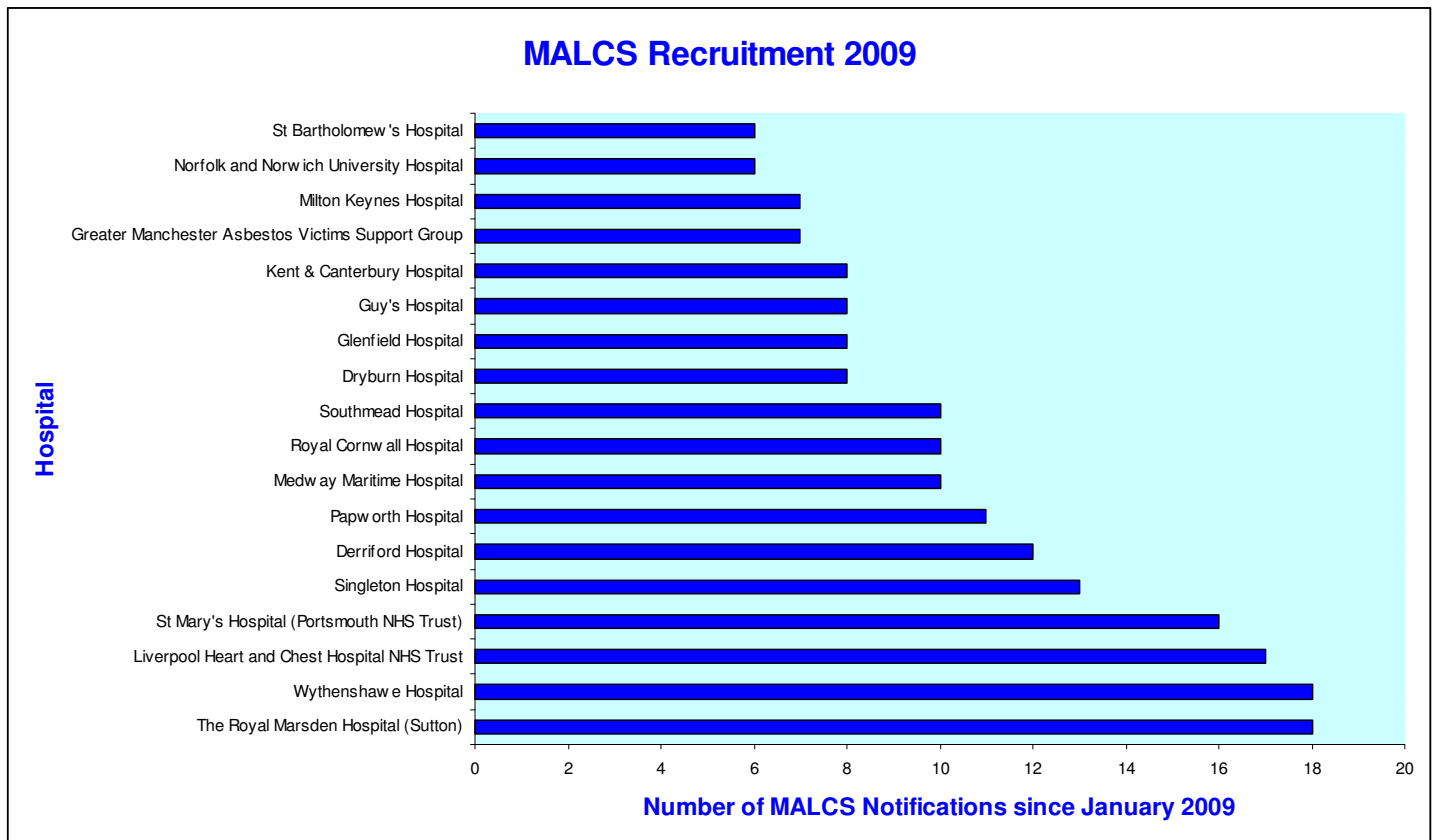
Mesothelioma And Lung Cancer Study – an NCRN postal survey

MALCS was set up to estimate the mesothelioma and lung cancer risks associated with specific occupations across Britain. Data is collected by postal questionnaire. Our analysis of the first 622 mesothelioma patients 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, we have received completed questionnaires from 129 male resected lung cancer patients, 177 male mesothelioma patients and 71 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 6 eligible patients since January 2009 are shown below:



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



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A note about Lung Cancer patient Eligibility:

We wanted to clear up any potential confusion about eligibility of lung cancer patients to MALCS. Lung cancer patients do **NOT** need to have had their tumour completely resected to be eligible for MALCS. Any male patient, born on or after 1940, with primary lung cancer who has had **ANY** surgery to remove some lung tissue over and above a small biopsy is eligible.

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

Coroner Reform Update

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

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

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



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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

Albany Lodge

a newly refurbished 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.



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Forthcoming Events

Advances in Thoracic Surgery
5th - 6th November 2009

Venue: The Royal Brompton, London

Website: www.thoracics.co.uk

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BTOG SCLC Study Day 2009
12th November 2009

Venue: Hilton, Paddington, London

Contact: Dawn Mckinley (BTOG) for details

Email: dawn.mckinley@uhl-tr.nhs.uk

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

Venue: Newcastle Marriott, Metro Centre, Newcastle

Website: www.nlcfn.org.uk

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British Thoracic Society Winter Meeting
2nd - 4th December 2009

Venue: Queen Elizabeth II Conference Centre, London

www.brit-thoracic.org.uk

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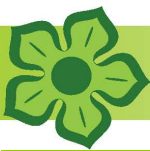


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8th Annual British Thoracic Oncology Group Meeting 2010
27th January 2010 – 29th January 2010

Venue: The Burlington Hotel, Dublin

Website: www.btog.org

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10th International Conference of the International Mesothelioma Interest Group
31st August – 3rd September 2010

Venue: Kyoto, Japan

Website: <http://www.congre.co.jp/imig2010/>

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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 Website: www.mesothelioma.uk.com

Helpline: 0800 169 2409

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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