

**Lyons Davidson's Specialist Asbestos Team, joined members and clients at Bristol & Beyond Asbestos Family Support's 4th Annual Patient and Carer Conference.**

Bristol & Beyond Asbestos Family Support (BBAFS) held their 4th annual Patient and Carer Conference on 14th March 2014 at Bristol Zoo Gardens. The day was once again well-attended with only a few people being put off by the foggy weather. Throughout the day, patients and their families were entertained and informed by a variety of speakers, who discussed research programmes, legal updates, treatment and future national events all on the theme of asbestos related illnesses. More importantly though, the event provided an opportunity for those suffering from asbestos related illnesses, such as mesothelioma, and their families to get together to share experiences and support each other.

BBAFS member and Honorary Secretary, Alan Baker, chaired the day and throughout the event Alan led group discussions and encouraged individuals to share their experiences.

**Sarah Smith, Lung Cancer Nurse Specialist, North Bristol NHS Trust: "James Lind Alliance - Priority Setting Partnerships"**

Sarah Smith, Lung Cancer Nurse Specialist (North Bristol NHS Trust) started the day off with an introduction to a new survey launched in February by the James Lind Alliance. The purpose of the survey is to improve the overall experience for patients and their families who are faced with a diagnosis of mesothelioma. Those behind the survey are hoping to identify the top 10 areas that need to be focussed on and where clinical research is needed.

Sarah led an interactive discussion and encouraged patients and family members to share their individual experiences in order to submit a collective response on behalf of the group. The main area of discussion was centred around the way in which the diagnosis is delivered to patients. It was agreed that there is a great need for training and consistency in how this news is given. It was also clear from the discussion that many carers find themselves feeling isolated and not knowing who to turn to during times when their loved ones are in pain and are in need of support. The group felt that it would be useful to have a list of out-of-hours contacts (GP, hospice, etc) so that medical and emotional support can be provided when it is needed most!

The results of the nationwide survey will be published later this year and it is hoped by all that improvements will be made to the diagnosis, treatment and care of mesothelioma sufferers.

**Alan Baker, Honorary Secretary, BBAFS: "Mesothelioma UK: Action Mesothelioma Day Planning Meeting"**

Alan Baker provided some feedback to the group about Mesothelioma UK's plans for 'Action Mesothelioma Day' due to take place on 4th July 2014. Alan attended the meeting in February 2014 where it was announced that new mesothelioma specialist nurses will be funded in Bristol, Oxford and Sheffield. This is great news for these areas, but Alan stressed the point that funds needed to be raised to pay for these nurses and to recruit more nurses in other areas.

The purpose of the 'Action Mesothelioma Day' is to help raise money for the charity but more importantly to raise the profile and awareness of asbestos related illnesses that affect hundreds of people each year. Alan welcomed any ideas from the group as to how BBAFS could mark this special event and to 'remember lost family members'.

Further information about the 'Action Mesothelioma Day' will be available on the BBAFS website [www.bristolasbestossupport.co.uk](http://www.bristolasbestossupport.co.uk) in the coming months.

**Ginny Chalmers, Head of Industrial Disease, Lyons Davidson: "The Diffuse Mesothelioma Payment Scheme"**

Ginny Chalmers was invited to speak about the new Mesothelioma Payment Scheme. This scheme has been introduced by the Mesothelioma Act 2014 which received Royal Assent earlier this year. Ginny provided the group with details of what is quickly becoming known as the scheme of last resort, including when an application to the scheme may be necessary.

Unfortunately there are times when a civil claim is unsuccessful and those suffering from mesothelioma are unable to receive compensation from their negligent employer. The scheme offers great news for those who would not normally be able to pursue a civil claim; however, it does not go far enough to compensate sufferers fully. Compensation is based on the age of the patient and represents approximately 80% of the average compensation received in a civil claim.

The clear message was that although applications can be made to the scheme by the sufferers or their dependants, it is important to instruct an Asbestos Specialist Solicitor, who has the resources to fully investigate the possibility of pursuing a civil claim.

**Mr Gianluca Casali, Consultant Thoracic Surgeon, University Hospitals Bristol NHS Trust: “Why not Surgery for Mesothelioma?”**

The most thought-provoking talk was delivered by Mr Gianluca Casali, who discussed the benefits and risks surrounding surgical intervention for the treatment of mesothelioma. After a brief lesson in the anatomy of the chest, Mr Casali explained the different types of surgery that are available for mesothelioma patients; however, available does not necessarily mean that surgery is offered. When assessing whether surgery is worthwhile, the surgeon will consider the benefits, including quality of life, pain relief and increased life expectancy, as well as the risks, which is linked to the aggressiveness of the treatment.

There are certain procedures that the majority of patients will undergo, such as pleural biopsies (either scan guided or thorascopic) to aid medical practitioners with diagnosing the disease. Some patients will have a talc pleurodesis to encourage an inflammatory reaction which triggers your body's defences and reduces the build up of fluid on the lungs. These are the less intrusive procedures where the benefits tend to outweigh the risks and actually assist in the diagnosis or improve the patient's quality of life.

More radical surgeries include parietal pleurectomies and decortications, whereby thick layers of tissue that are stopping the chest wall from moving and expanding are removed. Mr Casali confirmed that there is nothing more satisfying for a surgeon than seeing a lung expand after a decortication. However, although these surgeries can improve the patient's quality of life, they are extremely invasive procedures that do not cure the patient.

Mr Casali provided a brief summary of a recent trial called MARS I. This involved performing extrapleural pneumonectomies which involve removing the lung. This is extremely aggressive and radical. Statistics show that the prognosis is still only 18-24 months, similar to that for the disease itself. There is also a degree of pain and breathing difficulties following the surgery for the remainder of life. The study showed that after 12 months, nearly 50% of those who had undergone the extrapleural pneumonectomy had died, whereas only 30% of those who had not had the surgery had died. So can it be said that having your lung removed is worth it?

There is now going to be a further trial, MARS II, which will look at what happens to those who have pleurectomies and decortications as opposed to those who do not undergo this surgery. The group hope to invite Mr Casali back in the future for an update on this trial and developments in surgery.

**Sarah Smith, Lung Cancer Nurse Specialist, North Bristol NHS Trust: “Actively Living with Mesothelioma”**

The day ended, as it had started, with Sarah Smith providing the support group with practical tips for living actively with mesothelioma. Sarah explained that travel insurance providers for mesothelioma patients are always changing so it is good to shop around for insurance. She also gave the following advice to patients:

- 🕒 'Proper planning' is essential to ensure that difficulties are avoided.
- 🕒 Make things easy for yourself - use a wheelchair in the airport to avoid adverse symptoms.
- 🕒 Choose your destination wisely - consider countries where you can use your EHIC card or other countries who have similar arrangements.
- 🕒 Get a 'Fitness to Travel' letter from your treating doctor.
- 🕒 Take your medication with you and check that there are no restrictions on medications where you are travelling to and if there are then take a letter to explain your medication.
- 🕒 Take precautions in the sun, especially if you have had treatment for your illness.

For more information about the support group, upcoming events or the Patient Conference, please visit our website [www.bristolasbestosupport.co.uk](http://www.bristolasbestosupport.co.uk) or contact Rachael Wilson on 07544 213475 or by email [bristol\\_and\\_beyond@yahoo.com](mailto:bristol_and_beyond@yahoo.com).