**Bristol and Beyond Asbestos Family Support Group Patient Conference 2018**

Despite worries that the unpredictable British weather would snow off the event, members enjoyed a day of informative presentations, conversation, laughter and good food followed by a stroll around Bristol Zoo when we met on 5th March.

This was the 8th annual conference and it is wonderful to see how numbers have grown over the years, offering a valuable place to talk with other members and build firm friendships. Members also generously donated raffle prizes which raised over £160 to fund support group activities.

This is a really special group that members find invaluable. New members are always welcome from a very wide area and further information can be located on the website [www.bristolasbestossupport.co.uk](http://www.bristolasbestossupport.co.uk) or telephone Sarah Smith on 0117 414 1900 for details.

**Sarah Smith**, Lung Cancer Specialist Nurse at Southmead Hospital, welcomed members and started off the day with a helpful talk on how to get the most out of your doctor’s appointments. She would like patients to remember that the medical professionals are there for them and that they should arrive at the appointment knowing exactly what they want to get out of it. A list of questions and bringing a friend along is always helpful and careful planning of transport and timings helps to reduce stress so patients can concentrate on the appointment itself.

**Professor Nick Maskell**, Consultant Respiratory Physician at North Bristol NHS Trust followed with an informative and patient centred presentation on the new British Thoracic Society Guidelines. Professor Maskell was a co-chair of the guideline process and explained the extensive trawl through worldwide mesothelioma research which has recently been carried out to ensure that the guidelines result in the best possible patient pathway.

Some of the research and trials currently being carried out to improve the patient pathway further were explained:

* A ‘Target Trial’ is currently being carried out to investigate whether PET scans can help doctors to identify ‘hot areas’ to biopsy in order to reduce the risk of inconclusive biopsies.
* North Bristol NHS Trust is investigating whether the Mesothelin biomarker in the blood can help detect disease progression before this shows up on CT scans.
* Research is ongoing as to how to best manage patients’ pleural fluid. The guidelines recommend talc was the best agent for this but a recent trial was carried out to determine whether this is more effective when sprayed into the lungs during a thoracoscopy or whether it is just as effective to administer the talc through the indwelling pleural catheter which as great benefits for patient comfort and recovery if it is effective. The results will be out this October.
* A trial is due to start shortly to investigate a middle ground between aggressive surgery and talc pleurodesis. It has previously been found that surgery to strip the lining of the pleura has no benefit compared to talc pleurdesis but a middle ground may offer some benefits.
* An important French study has pointed to the possible benefit of adding a non-chemotherapy agent, bevacizumab, in to chemotherapy treatment to increase survival by 2-3 months. This drug is not yet approved in the UK for this purpose but this may change.
* A radiotherapy study has determined that there is no benefit in giving a prophylactic to the drain site of all patients and it is better for patients to have regular follow up with radiotherapy being given if it is needed. This also reduces inconvenience to patients of attending unnecessary oncology appointments.

**Anna Bibby**, Specialist Registrar, North Bristol NHS Trust presented a talk on the current immunotherapy and oncology trials ongoing in the UK at the moment. Presently there are 3 randomised first line trials as follows:

* Checkmate 743: This is an immunotherapy trial which combines two types of immunotherapy and compares this with a control group on chemotherapy. This is the only trial to compare a chemotherapy arm with a non-chemotherapy arm but participants must be willing to undergo chemotherapy in the even that they are selected for it.
* Lume-Meso: This is an anti-angiogenesis trial taking place in Leicester and London. It involves taking 2 tablets daily alongside chemotherapy and thus far has been successful in increasing the average tumour progression time from 5.7 months to 10 months.
* Atomic Meso: This is a targeted therapy for sarcomatoid mesothelioma. Previously there was little to offer patients with this type of mesothelioma so this is an exciting trial which has so far resulted in increased survival time from 12 months to 16 months.

There are also currently 2 second line trials underway. The first is known as VIM which is being carried out in Cardiff. The trial tests the use of chemotherapy agent Vinorelbine after the first line chemotherapy is complete. The Promise trial is also underway which involves immunotherapy treatment for patients who have already undergone first line chemotherapy. A third line immunotherapy trial is also underway at Cardiff.

Anna also explained that a non-chemotherapy trial called Assess Meso is to be run in Bristol. This is an observational trial for patients who do not wish to undergo chemotherapy and involves taking symptoms scores and measuring biomarkers and other aspects of disease progression. There is so much to be learnt about mesothelioma and the results from this trial will be valuable in ongoing research.

Embedded within the Assess Meso trial is a trial called TILT which will be investigating whether there is any benefit of placing dead bacteria down the indwelling pleural catheter in the hope that this will stimulate the immune response in the area without causing side effects to the rest of the body.

More information about current trials can be found on the Mesothelioma UK spreadsheet which is available on the website: [www.mesothelioma.uk.com](http://www.mesothelioma.uk.com) or by asking your treating physician.

**Anna Morley**, Respiratory Research Unit, North Bristol NHS Trust talked to us about her current research project looking in to the patient experience of procedures relating to pleural effusions and considering how this can be improved to prevent the need for emergency admissions. Members were given questionnaires to complete to assist Anna with this valuable research.

After a delicious lunch, **Bob Reeves** of the Anchor Society spoke to us about the importance of remaining or getting active in older age. The Anchor Society was founded in 1769 and concerns itself with the care of elderly people in the Bristol area. Bob focussed on the Active Ageing Bristol project which is a fully inclusive project to develop new opportunities to encourage people aged 55 and over to become and stay active. There are various walking sports and other activities currently happening across Bristol and new participants and volunteers are always welcome.

**Isabelle Selley,** Senior Associate in Irwin Mitchell’s Bristol Asbestos Related Disease Team gave a presentation about funding the cost of treatment where it is not funded by the NHS. The recent Irwin Mitchell case of Scott demonstrates that it can be possible to agree with the Defendant that they will pay for ongoing treatment as and when this is recommended by your treating physician although this is not often straight forward. For patients, the best advice is to keep your solicitor updated about your treatment and recommended treatment so they can make the best case on your behalf.

Finally, the day was closed with the Annual General Meeting where the committee were re-elected. BBAFS are always looking out for members who might be keen to take an active role in running the support group and anyone interested is encouraged to get in touch.