

Breathtaking



Newsletter of **Breathakers – Action For Bronchiectasis** support group

11th Edition
Summer 2016

This edition will see us through a, hopefully, good, if late, Summer.

In this issue we cover a well earned award, Research and Breathlessness & Exercise.

Mike Carey – Secretary, Editor.

Congratulations

As you will be well aware we, as patients, are lucky to be looked after by Dr. Adam Hill and his team. As a leading expert in Bronchiectasis and with an increasing patient base he is constantly busy dealing with the various aspects of this condition.

Well, all that hard work and dedication has been recognised as he was recently awarded an Honorary Professorship in Respiratory Medicine for his work with Bronchiectasis.

Everyone at 'Breathakers' sends Professor Hill many congratulations for this very merited award.

Research



Andrea, Elena, Sam

It may sometimes seem as if little, or nothing, is being done to improve things for Bronchiectasis patients but Dr. Hill and his research team are constantly looking at the condition from different angles.

Below is an example of some of the research that they have undertaken or which is still ongoing. If you would like to volunteer for any of the projects Andrea and Sam can be contacted on 07740-841-798 Mon-Friday 9-5 for Research questions, or email them on sam.donaldson1@nhs.net or andrea.clarke8@nhs.net

Research Projects:

1. Cathy our microbiologist continues her research into *Pseudomonas aeruginosa* and cross infection in Bronchiectasis. For this we require sputum samples from the patient group, can you drop these in at the monthly meetings?
2. We keep adding to our Bronchiectasis biobank to enable us to undertake large scale research projects from stored samples in the future.
3. In conjunction with Spanish colleagues we are about to recruit Bronchiectasis patients who we will closely monitor over 12 months. We will do detailed assessment at baseline, 12 weeks, 6 months and 12 months as well as gathering information on any infections over the 12 months. Patients will be offered 2 sessions to improve their awareness and understanding of Bronchiectasis.
4. We are currently recruiting to a world-wide Liposomal Amikacin study. This new formulation of the drug is being used to treat *Mycobacterium Avium* infections in patients with Bronchiectasis or COPD.
5. The Bronch UK study will start soon. It will offer patients a chance at more detailed

assessments and follow up and gather data at start and end of infections. The data gathered (Bloods, sputum, questionnaires, spirometry) will be combined with UK wide data and will link into the EMBARC study (European Bronchiectasis Registry). This will provide a huge Bronchiectasis Resource that will further Bronchiectasis Research greatly.

6. Beatriz a physiotherapist colleague from Spain has come to work with the Bronchiectasis team for 6 months as part of her PhD. She is going to start a study using autogenic drainage technique to aid sputum clearance. 50% of the patients recruited will be taught this new self management technique. If you are keen to take part in any of the research studies just call Sam/Andrea.

From The Clinic

Prof Adam Hill
Royal Infirmary
and University of
Edinburgh



When should I take antibiotics for chest infections?

One of the biggest questions I get asked is *when should I take antibiotics for a chest infection?* It is normal for patients with bronchiectasis to have symptoms of cough and sputum (phlegm) production on a daily basis. Your symptoms may change day to day so we normally wait 48 hours or longer before we would normally start antibiotic therapy.

Some chest infections are due to viruses and do not need antibiotics and you will get better on your

own.

Antibiotics are recommended, however, if you feel worse for two days or longer, with worsening cough and increased amount of sputum or change of thickness of your sputum- usually stickier- and increased colour of your sputum usually to dark yellow or dark green. Some may also have one or more of the following: increased wheeze (whistling noise when you breathe out); increased breathlessness; coughing up blood; feeling generally unwell; increased tiredness; feeling feverish.

What to do if you have a suspected chest infection? My advice is that you should see your GP as soon as possible. Please collect your sputum in a sterile pot (obtained from your GP or hospital) preferably first thing in the morning and take it to your GP.

Your GP will give you advice whether antibiotics are needed or not. Antibiotics are normally recommended for chest infections as highlighted in the above paragraph. In such cases antibiotics should be started urgently. You should not wait till the sputum culture results are back because that can take several days.

For chest infections, it is very important you do your chest physiotherapy at least twice daily. It is really important you take all the standard medication you are on and the prescribed antibiotics. Make sure in addition you take plenty of fluids so you do not get dehydrated.

To comment on or contribute to the newsletter contact;

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What antibiotics should I take and for how long?

For all those that attend our specialist bronchiectasis clinic, we give the GP clear recommendations what antibiotics to prescribe for you if you develop a chest infection and how long to give the antibiotics for.

The antibiotic choice is usually based on your previous sputum samples you bring to clinic that we have sent to the microbiology laboratory. The duration of antibiotics depends on the severity of your bronchiectasis and for patients with more advanced bronchiectasis we normally recommend 14 days of antibiotics.

My GP recommended hospital admission for my chest infections- why?

Some people get very ill with chest infections and need hospital admission. In addition some patients do not respond to oral antibiotic therapy or they have organisms that are resistant to oral antibiotics and necessitate hospital admission or hospital based outpatient treatment. We now have a service where you can deliver your own intravenous antibiotics at home instead of coming into hospital- see www.bronchiectasis.scot.nhs.uk.

Breathlessness & Exercise

Breathlessness. What does that mean for you? Well, as far as exercise is concerned, whether you have a lung condition or not it is perfectly normal to be breathless while doing it.

For people with a lung condition it is very important to try to be as active as possible. It is the old 'use it or lose it' syndrome. If you just sit around and not attempt to do anything physical your lungs will just become weaker because you are not using them as much as you should be.

One of the most important points is knowing your limits and therefore not overdoing it. When you are doing any exercise you should still be able to have a

conversation, if not, you should stop. You should try to just get moderately breathless. In this way you are giving your lungs the right amount of work to do without doing too much.

If you are quite breathless then you can lean forward on a bannister, window ledge, kitchen unit or something similar as this will expand your lungs making it easier for you to recover (watch athletes after they have finished a race, they bend forward to achieve the same thing).

Important Before taking up any new form of exercise consult your GP or Consultant.

Salad Days

No recipe this time round but how about throwing together a lot of ingredients to make a hearty salad. You can add interest with any other items you like such as Ham, Fish, Cheese or any other food that you like varying it each time to keep it interesting. Think healthy.

Breathbusters - Action For Bronchiectasis

2016 meetings of Breathbusters - Action For Bronchiectasis support group

The group meets on the last Tuesday of each month, January – November with our Christmas Get-together in December. All meetings are held in RIE, Seminar Room 1640 (opposite ward 203), followed by tea/coffee and refreshments and a chance to chat.

Jan. 26th - Quiz.
Feb. 23rd - Dr. Hill. developments
Mar. 29th - Lead Nurse & Physio.Clinic
Apr. 26th - Prof. Nick Bateman.
May 31st - Living with Bronchiectasis.
Jun. 28th - Dr. Pallavi Bedi
Jul. 26th - Dave Bertin, CHSS.
Aug. 30th - Dr. James Chalmers.
Sep. 27th - Nicola Cotter
Oct. 25th - AGM
Nov. 29th Patient Experience
Dec. -Christmas Party

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