



Breathtaking

15th Edition

Winter 2018/19

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

This edition of Breathtaking is very much about one man, Professor Adam Hill.

Breathtakers began in 2010 and in its eight years its existence & success is very much due to his help & backing.

Sadly (for his patients) he is now moving on to a new position. We all wish him great success in his new post.

Below is his latest article.

Mike Carey – Secretary, Editor.

THE BRONCHIECTASIS SERVICE

I started in 2001 and built up the Bronchiectasis



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service from scratch and it now has over 1,300 patients. This has been a huge success and we are the specialist centre for Bronchiectasis and see many patients from different health boards around Scotland. There have been a huge number of developments since 2001, and I will highlight some of the key developments....

Local Developments;

1] we have developed and now have an excellent multi-disciplinary team. The Bronchiectasis team consist of myself, Ximena Recabarren (a GP with a specialist interest in Bronchiectasis), Ruzanna Frangulyan (an associate specialist), a Respiratory Registrar attached to our firm, a Respiratory Nurse Specialist (Kim Turnbull), a Physiotherapist (Jo Pentland) and a Pharmacist (J. Scott).

2] the ability for patients or a family member to deliver intravenous (into the veins) antibiotic therapy at home rather than be admitted to hospital for 14 days.

3] the ability for patients to receive inhaled antibiotics (such as Gentamicin and Colomycin) via a nebuliser for patients with advanced Bronchiectasis with repeated chest infections.

4] link in with our primary care colleagues via the Respiratory Managed Clinical Network, to allow seamless care between primary and secondary care.

5] strong link with patients- we have developed a patient website www.bronchiectasis.scot.nhs.uk Bronchiectasis – A patient's guide to managing and living ...

This website is a joint collaboration between Bronchiectasis patients and the clinicians who treat them. The aim is to share widely the experience which has been built up in recent years in the treatment of Bronchiectasis at the Royal Infirmary of Edinburgh clinic and to share this with a wider audience.

Affiliated to:
Chest
Heart &
Stroke
Scotland



And the patients run regular educational meetings throughout the year and produce a regular newsletter.

UK Developments;

1] I have led 2 British Thoracic Society Guidelines in Bronchiectasis. These national guidelines guide the management of Bronchiectasis not only in the UK, but my international colleagues comment they are used throughout Europe and USA as well.

This is the link for the first guideline <https://www.brit-thoracic.org.uk/document-library/clinical-information/bronchiectasis/bts-guideline-for-non-cf-bronchiectasis/> . The latest guideline has been accepted for publication by Thorax and will be published in 2019.

2] I have led British Thoracic Society Quality standards for Bronchiectasis- these have been excellent and highlight how we should be managing patients throughout the UK. This is the link- <https://www.brit-thoracic.org.uk/document-library/clinical-information/bronchiectasis/bts-guideline-for-non-cf-bronchiectasis/>.

3] I have led UK audits in paediatric and adult bronchiectasis in the UK which audit how we manage bronchiectasis in the UK. Results of the latest audit are in the link here- <https://www.brit-thoracic.org.uk/document-library/audit-and-quality-improvement/audit-reports/bts-bronchiectasis-audits-combined-report-2017/> .

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Research;

Thank you all for participating in all the research studies to date. The studies currently ongoing in Bronchiectasis are:

1] Biobank of blood and sputum samples in patients with Bronchiectasis.

2] A study comparing standard 14days intravenous antibiotics compared with a shortened course.

3] A study investigating replacing

Immunoglobulin replacement in patients with Immunoglobulin deficiency in Bronchiectasis.

4] A study investigating Haemophilus species, the commonest organism identified in Bronchiectasis.

5] A UK wide study called BRONCH UK, which will be a UK biobank for patients with Bronchiectasis.

6] A study investigating inhaling saline or taking tablets to aid mucus clearing.

7] International studies investigating inhaled colomycin and tobramycin.

There are many others....

Future Plans;

I now have a new position as Post Graduate Dean for East of Scotland (Edinburgh, Fife and Lothians). I am continuing my academic work at the University of Edinburgh and will continue to support the Bronchiectasis service. There are ongoing plans to develop the Bronchiectasis service, and more news will follow.....

Professor Adam Hill

Royal Infirmary and University of Edinburgh

Share Your Feelings

When we (your Committee) man the table each Month in Outpatient Clinic 3 we quite frequently meet people who have been newly diagnosed with Bronchiectasis who obviously are not fully aware of what this means.

Being told that you have a chronic condition that you have probably not even heard of can be very bewildering. Confusion, worry even being scared of what might be, are a few of the emotions that you may have.

And that is why it is so important that you share how you feel with someone. This can be a partner, local GP or other Members of the 'Breath-takers' support Group.

This is one of the reasons that the Support Group is so important as Bronchiectasis sufferers can see when they attend our meetings

that there are people who were diagnosed with the condition 10, 20, 30 or more years ago and that they are living a relatively normal life.

And discussing their own experience of Bronchiectasis with other members and hearing how they manage the condition can allay many of their original fears.

So don't keep any fears, worries or concerns to yourself, speak to someone, anyone, as there is much help out there. Be it, Chest Heart Stroke Scotland (CHSS), GP, 'Breath-takers or Friends & Family.

2018 AGM

October saw us hold our annual AGM led by our Chairman, James Wildgoose.

He informed the members of a number of items including;

1. Proposed reduction in number of 'Breath-takers' Monthly meetings in 2019 (not meeting in January, July & August). This was agreed by the members present.
2. The re-establishment of the Managed Clinical Network (MCN).
3. The idea of establishing a 'Help Line' for newly diagnosed patients.
4. We also welcomed Anne Mackay onto the Committee.

Winter Tips

The cold, damp Winter months are a time when anyone with a respiratory condition is very vulnerable. So, as well as getting the Flu Jab there are things that you should be doing to help get you through this period.

Keeping warm is important, as is making sure that you get the right nutrition. A good way of doing this is to adopt much of the 'Mediterranean Diet'. This means incorporating more Fruit, Vegetables, Fish, Beans & Pulses, etc. into your meals. Items can often be added to soups & puddings.

Below is a hearty soup to begin with

Tattie Drootle

1lb/450g Peeled Tatties
1 large Leek, washed and chopped
1 large Onion, peeled & chopped
1oz/25g Butter (must be butter for the flavour)
2pts/1ltr Chicken Stock
1tbsp Single Cream
1tbsp chopped Parsley
Salt & Pepper

Method:

Fry the prepared onion and leek in the butter until soft but not discoloured. Break or cut the tatties into large chunks and add to the onion and leek with the stock. Season and simmer gently for about 1-1¼ hours. The tatties should have broken down at this stage. Remove from the heat and stir in the cream. Re-heat but do not allow the soup to come to the boil again. Serve hot, garnished with parsley.

Some tatties break down better than others for this recipe, if they don't, break down, just break them into rough chunks using a fork.

2019 meetings of Breath-takers - Action For Bronchiectasis support group;

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

2019 Meetings Agenda

Jan. No meeting.
Feb. 26th, Devs. In Bronch. Prof. Hill
Mar. 26th, Physio. Wendy White
Apr. 30th Yellow Card Alison Paterson
May 28th Patient Story, Mike Carey
Jun. 25th Research Prof, J. Chalmers
Jul. No meeting.
Aug. No meeting.
Sep. 24th MCN James Wildgoose
Oct. 29th AGM & Discussion
Nov. 26th TBA
Dec. 12th Christmas Get-together