BREATHING MATTERS
NEWSLETTER: ISSUE 13

AUTUMN 2014

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We wish our supporters a merry Christmas

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Fighting pulmonary fibrosis and infection

#Breathtember Goes Global



Breathing Matters would like to thank our fabulous supporters who helped raise awareness of **pulmonary fibrosis** through the medium of twitter. Tweet power spread the word all over the globe by retweeting the term **#Breathtember** throughout September.

Supporters 'got out of breath for #Breathtember' by running, cycling, trekking, playing golf, and some by just simply climbing the stairs or blowing bubbles!

Breathing Matters would like to thank all our #Breathtember champions for their help in making this year's awareness campaign a resounding success.

New Therapies in Pulmonary Fibrosis

Historically, drug treatments for IPF (idiopathic pulmonary fibrosis) have been limited with mixed evidence for many of the drugs used. We have eagerly awaited better therapeutic options and, in May 2014, at the annual American Thoracic Society, new clinical trial data was presented that realised those hopes.

There are now two new potential medications available. The first of these, pirfenidone (Esbriet) was approved by NICE in 2013 and is available to specific IPF patients in the UK. There have been several clinical trials with the most recent one confirming a positive effect. When looking at patient's breathing tests (in particular the forced vital capacity (FVC), shown to correlate with progression) those taking the medication had around a 50% reduction in decline compared to those taking placebo over the course of one year. Like all medications there are side effects predominantly rash (often triggered by UV light i.e. sunlight), indigestion and loss of appetite.

The second drug, Nitedanib (Ofev) was only approved by the US authorities in October 2014 and is not yet available for general use in the UK. The European Medicines Agency recently agreed to an accelerated review and if, approved, this will be followed by a NICE appraisal in 2015. In a large combined trial of over 1000 patients, it also demonstrated a significant reduction in the decline of FVC, again around a 50% reduction. Diarrhoea was reported by 60% of patients although only a small number of these (5%) had to stop the medication because of it.

Whilst we still do not have a cure for the disease and these new treatments only slow progression, they herald a new era for IPF. We are increasingly better informed about what causes the disease and increased interest on a wider scale means earlier, more accurate diagnosis and potential funding to help the discovery of even better treatments.

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THE CHRISTMAS SONG QUIZ

- 1. How many times does Santa check his list?
- 2. Good tidings to you and all of your what?
- 3. On the eleventh day of Christmas, what did my true love send to me?
- 4. I'm dreaming of a White Christmas with what?
- 5. Why do I want my two front teeth for Christmas?

Answers can be found on our website www.breathingmatters.co.uk

Christmas Is Coming-We Can Help!



It's time to start writing your Christmas list, time to start your Christmas shopping, time to work out which relatives you are visiting this year and time to order your **Christmas cards!** Breathing Matters can help you with the latter.

This year, we have a number of options. You could order directly online with www.charity christmascards.com They sell both paper cards and, for those of you who are more green in nature, they also provide online cards to email to your friends and family. They also supply corporate cards so you can put your company name on the front cover. **Up to 50p per card is donated directly to Breathing Matters.**

Our other option, this year, is to purchase handmade and vintage Christmas cards through Jane Walker. Some of you will know Jane from her lovely breathing Matters designer stalls at Easter and over the summer at UCH. Jane has two Christmas stalls organised on Friday, 7th November 2014 and Friday 12th December 2014, 10am-2pm at UCH Atrium, where she will be selling these cards along with some fabulous and unique stocking fillers.

If you are not able to get to these stalls, Jane has very kindly agreed to take orders and she will personally post these to you. All profits of these sales will go to Breathing Matters. Designs and contact information is on our website: http://bit.ly/1twjV9k

Please remember to use Give As You Live for all your online Christmas shopping and a percentage of every sale goes to Breathing Matters.

Visit our website on www.breathingmatters.co.uk





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UCL Respiratory, Rayne Institute, 5 University Street, London WC1E 6JF Email: breathingmatters@ucl.ac.uk

You can simply DONATE via www.justgiving.com/breathingmatters



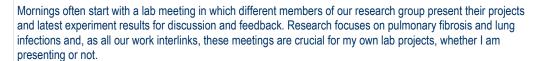
JustTEXTGiving is now available to Breathing Matters supporters.

Simply Text 'BMPF22 £xx' to 70070



A Day in the Life of Breathing Matters' Clinical Fellow, Dr Theresia Mikolasch

My day as a Breathing Matters' Clinical Fellow is a busy one. I divide my time between the Centre For Inflammation and Tissue Repair, a basic science laboratory at UCL, and UCH hospital.





I then go over to UCH to see patients in the clinic who require a cryoscopic lung biopsy to diagnose their underlying lung disease. I take a full history to ascertain whether there are any clues in my patient's environment or life style which could point towards the cause of their lung problems. I also examine them physically to make sure they are well enough to undergo a biopsy. I spend at least half an hour explaining the procedure to them in detail. I also spend time recruiting patients to several research projects and collecting blood samples for analysis in the research lab. I then go to the endoscopy department to perform bronchoscopies and collect further samples for research.

Lunchtime is often filled with clinical and educational meetings, such as the chest x-ray meeting where all respiratory doctors discuss interesting cases with their colleagues in conjunction with our specialist radiology doctors. These discussions usually lead to a new plan for investigation and treatment for the patients concerned and are one way for me to identify patients who might benefit from a bronchoscopic biopsy.

Afternoons are usually spent in the lab running experiments and tending to my growing cells. This is rather akin to gardening and I have convinced myself that talking to them in the incubator makes them grow better! In between all that, I try to squeeze in paperwork and reading of newly published research articles.

Every day as a Breathing Matters' Clinical Fellow is unique; bringing its own challenges, opportunities to learn and very many rewards.

FUNdraising Events, Tributes and Inspirations

- Organise a Christmas decoration making evening with mulled wine and mince pies.
- A nail art event at your own home, getting ready for Christmas.
- A swish party to swap unwanted clothes for free; just pay an entrance fee.
- A coffee and cupcake morning or a Bake-Off.
- A Santa run.
- A hike, a cycle, a climb, a hop be as outrageous or as simple as you dare!





A massive thank you to the Tough Mudder half marathon obstacle team organised by Adam Clark who has raised almost £5000 for Breathing Matters.

We hope all the aches and pains were worth it!

HOLST SINGERS CHARITY CHRISTMAS CONCERT



We are excited to announce that **the Holst Singers** (one of Britain's foremost choirs) will be giving a **Charity Christmas Concert in aid of Breathing Matters**. The concert will take place on **Friday**, 5th **December 2014 at 7pm** in the new Pavilion in the grounds of University College London, Gower Street.

Tickets cost £35, which includes light refreshments served at 7pm. Seating is unreserved. Contact Donna Basire at breathingmatters@ucl.ac.uk

More information can be found on our website at http://bit.ly/1vSOqj5