BREATHING MATTERS NEWSLETTER: ISSUE 19

AUTUMN 2016



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For more info on our Christmas Appeal visit: http://bit.ly/2fwtliC





- 1. 1964 James Bond movie
- 2. Pyrite
- 3. 1849 California event
- 4. What King Midas had
- 5. Kanye West song
- 6. Former name of Ghana
- 7. Oil
- 8. Francis Drake's ship
- 9. San Fran bridge
- 10. What our supporters have

Answers on our website www.breathingmatters.co.uk

Bronchiectasis Supporters' Evening

There was a lively Q+A session after Professor Jeremy Brown's presentation at our Breathing Matters Bronchiectasis Supporters Evening in September.

"How do we know when to start antibiotics?" "What information will the newly opened Bronch UK study show?" "What can we do to help?"

The evening started off with a very personal story of bronchiectasis from Jane Walker, who is a patient at



Guests were then treated to a tour of the refurbished laboratories.

Thank you to Sainsbury's Warren Street for sponsoring our evening.

Help us Find a Cause for IPF

At present, we do not know the exact cause of idiopathic pulmonary fibrosis (IPF), although research has identified lots of processes that are likely to be involved. Currently, we believe that microscopic injury occurs in patients with IPF and then the body responds to repair this, but does so in a way that leads to more damage and scarring. One of the processes involved in the repair pathway is coagulation, which minimises blood loss when tissues are damaged.



Researchers have shown that clotting is over-activated in IPF patients and we want to investigate how reducing this might improve the disease. We are asking patients from our UCLH clinic if they would be willing to take a medication for 3 to 4 weeks, which reduces clotting. We will perform blood tests and two scans before and after taking the drug to judge response.

We are raising money in this year's Christmas Appeal to fund this study. For more information, visit our website: http://bit.ly/2fwtliC or contact us on breathingmatters@ucl.ac.uk

Christmas Charity Concert

Come along to our Charity Christmas Concert : "A Christmas Celebration with the Holst Singers."

This interactive concert will take place in the iconic St Paul's Church in Covent Garden on Friday, 9th December 2016 from 7.30pm.





The Holst Singers have been described by the BBC as 'a leading chorus on an international stage' and are renowned for their dramatic and engaging performances. 'Mesmerising' and 'atmospheric'.

Tickets are £25 each and are available from http://bmchristmas.bpt.me/

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



JustTEXTGiving is now available to Breathing Matters supporters.

Simply Text 'BMPF22 £15' to 70070



A Day in the Life of a Research Registrar by Dr Helen Garthwaite

My typical day starts trying to remember exactly where I need to be! I am based at two different sites and have several shared desk bases at each so I am relatively nomadic and no single day is the same. Two days of the week, I am in the clinic seeing patients, which is definitely my comfort zone after 10 years working as an NHS doctor. In clinics, I assess patients, discussing treatment options with them, but also always thinking about research projects that they might be able to take part in.



When I'm not doing that, I'm collating data from those research projects, in particular looking at special scans and getting information from them that we hope will change the way we assess pulmonary fibrosis patients in the future. I also spend time putting the data together and sending our work to journals and conference meetings so that we can share our experience.

A large amount of my time is spent on new research projects, meeting with potential collaborators and trying to direct all those ideas. This essentially means lots of time completing grant applications, designing protocols and dealing with the regulatory bodies. Even the most simple projects take a lot of time and often some blood, sweat and tears to get them up and running. There are so many enthusiastic people working in pulmonary fibrosis that most weeks include meeting with someone new and talking about where we go next with our work.

One lesson I have learnt during this post is to never say no to an opportunity, and meeting new people to work with is so key. I also spend time interacting with the nurses and other professionals, thinking about how we can improve the clinical service; to me, this is just as important as the research since the patients are, and should always remain, at the centre of my day-to-day work.

FUNdraising Events, Tributes and Inspirations

- Organise a Mulled Wine and Mince Pie Evening.
- Or a Christmas Arts and Crafts Evening.
- Organise an Autumn Harvest Festival, or perhaps a festive Christmas Carol Evening.
- People love cakes at any time of year; have a Cake Sale.
- Buy our Christmas Cards; both paper and online cards are available on our website: http://bit.ly/2fXNUYB

#BREATHTEMBER

We renamed September 'Breathtember'; global pulmonary fibrosis awareness month.

Thank you to our supporters who joined in with this year's challenge of 'Getting Out of Breath for #Breathtember' and for tweeting and retweeting your efforts.

This year's #Breathtember Champion was Colin Cargill who tweeted while he cycled from Marseilles to Barcelona with his Colt team work colleagues. Well done Colin; you're a trooper!

The term '#Breathtember' was retweeted more times than ever before; so thank you all for spreading awareness of this dreadful disease!

OPEN CHALLENGES



Why not challenge yourself in 2017 to a more bespoke charity event?

Breathing Matters have teamed up with Global Adventure Challenges. Have you ever wanted to trek the Great Wall of China, cycle from Yosemite to San Fran or raft on the River Zambezi? GAC can organise this for you and money raised will go to Breathing Matters.

For more information, visit: http://bit.ly/1UpZxBx