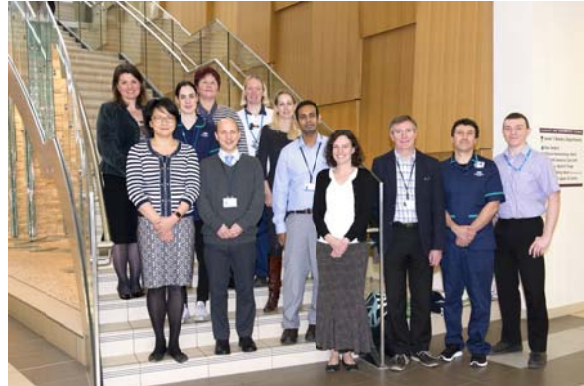


# The (not quite inaugural) Oxford Pulmonary Fibrosis Support Group Newsletter

I hope you all have had a very fine festive season. The New Year is now well upon us and with it resolutions. I have made several, most of which are unfortunately already consigned to the wastepaper basket of history. Though to be honest as I am writing this before Christmas, it appears I have already dismissed them before 2016 has even started... However, one that I had every intention of keeping is to pilot a newsletter which can be shaped by our support group, reflects our interests, as well as being a means to capture and distribute the outputs from our meetings.

I have looked at newsletters from support groups across the patch. I was primarily doing this to 'borrow' some of their best ideas. They are all rather fine with a diversity that I guess reflects the needs and interests of their members. A contact details section seems universal and I have included an embryonic one here. They also have an unfortunate habit of putting ILN nurse pictures in. So if this newsletter thing is to progress, I will have to arm-twist Dr Hoyles into buying some form of Photoshop package to carry out some heavy duty airbrushing. (For me of course, not Ophelia).



Team Oxford ILN for 2016

A 'things we are up to' section also seemed like a rather appropriate thing for a newsletter. I must admit I have absolutely no idea what any of you are up to and no doubt you would be somewhat unnerved if I did. So as the only person I know about is me then I guess I should let you know what I'm up to.

I initially asked my elder daughter what interesting thing about me I could mention. Her response was an utterly blank look, followed by questioning if this was the sort of thing I did all day. I of course informed her of the breadth of skills required by a modern nurse but by the time I was half way through my lecture she had already plugged herself back into her iPod.

As my search for something interesting to tell you about has thus far proved fruitless, I have decided to shamelessly manufacture something. The aforementioned something is to 'run' the Edinburgh marathon in aid of both the BLF and Action for Pulmonary Fibrosis. This felt like a rather fine idea as I was staring at a website full of the happy faces of last year's finishers. Now in the cold light of day I am not quite so sure... but in any case I have at least put a metaphorical tick in the 'interesting' box.



A fine example of a group of people doing something 'interesting'. Please do not feel compelled to take up an art class as other forms of 'interesting' are of course available.

## Meeting dates for 2016 and beyond...

Here are the dates for the support group meetings for the coming year and early 2017. They continue to be on the second Thursday of alternate months, though the keen eyed of you will notice that the June meeting is on the third Thursday. (Sorry... someone had got there ahead of me in booking the hall).

Thursday 11<sup>th</sup> February 16  
Thursday 16<sup>th</sup> June 16  
Thursday 13<sup>th</sup> October 16  
Thursday 9<sup>th</sup> February 17

Thursday 14<sup>th</sup> April 2016  
Thursday 11<sup>th</sup> August 16  
Thursday 8<sup>th</sup> December 16  
Thursday 13<sup>th</sup> April 17

## An 'a capella' December meeting

Thanks to all of you who attended the last group meeting. I very much enjoyed it and was pleasantly surprised by the quality of sound we collectively made during the singing for better breathing taster session.

As was mentioned, Singing for Breathing came out of a piece of research from the Royal Brompton Hospital. The aim of which is to enhance existing physiotherapeutic support for respiratory conditions by introducing individuals to a new form of informal exercise, and teaching a better understanding of breath control through the use of the voice. I hope you all found it both useful and enjoyable as well as reinforcing the importance of breathing techniques. If you would like any additional support with breathing techniques then please contact Rachel Lardner via the helpline and she will be able to provide some comprehensive advice.

For more information on singing groups across London and the South East please go to:

<https://www.blf.org.uk/Page/Singing-Groups#London>



Unfortunately I didn't take any pictures so can't illustrate this with what we looked like; however, in order to fill what would be an unfortunate gap, this is an example of what such a group looks like in Lambeth.

## Questions with at least some attempt at an answer...

In December we also had what I thought was a really grand question and answer market place. The idea was to bring questions we had about living with pulmonary fibrosis and trade them for answers from group members who may have already faced them. I have captured the outputs below. I have also done my best to search around to provide additional details for some of the answers but unfortunately there is no guarantee these answers are comprehensive.

### 1. Going Abroad with Ambulatory Oxygen.

The British Lung Foundation highlights the need to make arrangements for oxygen to be provided at your destination before you travel. UK suppliers will not be able to provide oxygen while an individual is overseas. Within Europe, oxygen can be arranged through the European Health Insurance Card (EHIC) scheme. Further details about this can be found through the BLF website

<https://www.blf.org.uk/Page/Going-on-holiday-practical-issues>

or through their helpline on 03000 030 555.

Outside of Europe your usual UK supplier may have direct contact with a company or the BLF suggest contacting the British consulate in the country you are travelling to. Again their helpline on 03000 030 555 can also help.

### 2. Flying with ambulatory oxygen.

This appears to be airline specific and the constant piece of advice is to check with an airline early on. The European Lung Foundation has details of the oxygen policies of over 100 airlines and can be found here.

<http://www.europeanlung.org/en/lung-disease-and-information/air-travel/airline-index/>

### 3. Are all those with Pulmonary Fibrosis Aware of Diaphragmatic Breathing?

Please contact Rachel Lardner via the usual helpline or e-mail address to arrange a 1:1 discussion and assessment if you are interested in this.

**4. What is the difference between the various oxygen concentrators available?**

The flow of oxygen required will be the key factor regarding size. For those requiring relatively low flow rates then smaller concentrators are available; higher flow rates will require a larger device. Please contact your local oxygen nurses for further details.

**5. The battery life of an oxygen concentrator is becoming more limited what can I do?**

I am afraid the best I could come up with here is to suggest a discussion with your oxygen nurse.

**6. How to find Travel Insurance?**

As you will no doubt be unsurprised to hear getting a comprehensive answer is pretty much impossible; however, the British Insurance Brokers Association (BIBA) can identify brokers who can provide advice on this.

British Insurance Brokers Association  
8th Floor John Stow House  
18 Bevis Marks  
London  
EC3A 7JB  
Phone: 0870 950 1790 (open 9am to 5pm Monday to Friday)

Email: [enquiries@biba.org.uk](mailto:enquiries@biba.org.uk)  
Website: [www.biba.org.uk](http://www.biba.org.uk)

I understand that brokers make a service charge so it is probably worth looking at a number of them to make sure you're aware of any charges in advance of using one and ensure they sufficiently understand your circumstances.

The British Lung Foundation can also give advice on this via their helpline: 03000 030 555.

The two companies mentioned by group members are: Forces Pension society (for those with a link to the armed forces) and Stay Sure Insurance. Here comes the big health warning: As I am not an insurance broker I am completely unqualified to give any advice or recommend particular companies, so please treat this as a broad selection of information which I hope is of some help.

**7. How do you get a blue badge and where can you park with one?**

The link below takes you to the gov.uk website where you to find tailored information on the blue badge scheme based on a postcode you provide. I tried with Reading and Oxford and it took me to information on both how to get a blue badge, eligibility criteria and where a particular council will allow you to park.

<https://www.gov.uk/where-registered-disabled-drivers-can-park>

**8. What would happen to my treatment at the Oxford ILD service if I moved?**

Please contact the service via the helpline and to seek clarification regarding how your new location relates to the area covered by this service.

## Medicine and Me: Living with Pulmonary Fibrosis



Medicine and Me is a series of events organised by the Royal Society of Medicine and there is an upcoming one on living with pulmonary fibrosis. I have included some information from the Royal Society of Medicine below which hopefully provides a flavour of the event.

*The aim of these events is to provide an open environment in which the patient's voice is given top priority. They give patients the opportunity to learn more about the latest treatments and research for their particular condition as well as allow healthcare*

Issue 1 January 2016

*professionals to hear first-hand from patients and their families about their concerns and experiences.*

The real plus is that it is free for both patients and carers. It takes place at the Royal Society of Medicine, which is at 1 Wimpole Street. Now those of you who have a similar level of 'knowledge' to your average London cabbie will have already realised this is actually marvellously close to Oxford Street, if that is in anyway your sort of thing.

It is a half-day event on 26th April 2016, which is just after our April meeting but perhaps if anyone does attend they could feedback to the group at our June meeting. I am very much hoping to go myself, though I must admit I have yet to ask either Dr Hoyles or Dr Ho about all this. I guess this will be the sort of question you ask just after you've made them a cuppa. The link below will take you to the relevant information, with details about speakers, timings and how to book.

<https://www.rsm.ac.uk/events/events-listing/2015-2016/groups/public-engagement-programme/mmg03-medicine-and-me-living-with-pulmonary-fibrosis.aspx>

### **And finally...**

Firstly, I should very much thank you for making it to the final section. Having read this far, you may well be experiencing a number of emotions; probably with an associated strapline of 'who on earth does he think he is expecting me to read this sort of stuff?' In my defence I have put this together partly because there were quite a few things I wanted to convey but also as an exemplar of what we could collectively produce, almost certainly with more finesse than I have. If having read this you would like to have a go at taking this forward in a more eloquent fashion then please let me know; my hope is that anything we produce would have contributions from multiple group members.

Also the support group itself, if it is to continue to meet the needs of its members would benefit from continued shaping by its members, perhaps with some of us taking ownership of particular aspects. If you feel you could contribute in any way however small, then please let me know. My thought is to have a short get together at the end of our February Meeting with anyone who is interested.

And finally... the ILD team would like to wish all of you the finest of New Year's.

### **Contact and Useful Links**

Oxford Interstitial Lung Disease Service  
Oxford University Hospitals NHS Foundation Trust  
Specialist Nurse Direct Line  
Ophelia English / Carmine Ruggiero  
01865 227050  
[Oxford.ILD@ouh.nhs.uk](mailto:Oxford.ILD@ouh.nhs.uk)

British Lung Foundation  
[www.blf.org.uk](http://www.blf.org.uk)

Action for Pulmonary Fibrosis  
<http://www.actionpulmonaryfibrosis.org/>

Age UK  
[www.ageuk.org.uk](http://www.ageuk.org.uk)