



## Fighting Pulmonary Fibrosis and Infection

### UCLH Charity Bike Ride 2011

Everyone came out in force for the second annual UCLH Charity Bike Ride, despite the June rain! Almost 100 cyclists came to ride 7 miles around the beautiful Richmond Park on Sunday 12<sup>th</sup> June 2011 in support of four funds within UCLH Charities; Breathing Matters, Leukaemia and Lymphoma Unit, Rays of Hope and TTP Research.

The cyclists included patients and their relatives, doctors, researchers and families with children as young as 7 years. One of our cyclists, Malcolm Weallans, rode with an oxygen cylinder on his back!

The adverse weather seemed to bring out a higher sense of achievement and there was definitely great camaraderie enjoyed by all. At the end, everyone was covered with mud, but still smiling. Those mud splatters will definitely take a few washes to come out!

Breathing Matters raised £11,000. Thank you to all our supporters who donated and urged others to support us ... you know who you are!

£10,000 of this money will go towards much needed platelet research into pulmonary fibrosis. You can find more info on this research on our website.

If anyone didn't get a chance to sponsor Jo Porter's Team- please visit [www.justgiving.com/drjoannaporter](http://www.justgiving.com/drjoannaporter)



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#### SUMMER QUIZ

##### WHERE ON EARTH?

In which cities would you find the following?

- The Acropolis
- The Forbidden City
- Alhambra Palace
- Sugarloaf Mountain
- The Blue Mosque
- St Mark's Square

Answers can be found on our website -

[www.breathingmatters.co.uk](http://www.breathingmatters.co.uk)

### A Day In The Life Of ... A Patient – Lawrence Matz



My name is Lawrence Matz and I was diagnosed with Pulmonary Fibrosis in October 2009. I was quite stable for the first 15 months, but this year I've gone rapidly downhill. I'm blessed with a wonderful family, especially my wife Gloria, and the most amazing friends. My fantastic Consultant, Dr Joanna Porter, has also made this journey easier to deal with.

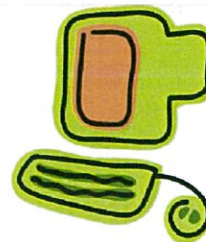
A typical day for me at the moment would be to get up about 7.30am and head off to the bathroom to shave and brush my teeth—that takes a lot out of me even though I'm on oxygen 24/7. Then it's into the shower. Gloria won't allow me to go alone and she washes and dries me and then helps me to get dressed ... sounds fun, but I wish I could do it alone ... if you know what I mean. All this, even though assisted, knocks the stuffing out of me and my sats can go down to about 65 even with the oxygen ...not easy! I then go down to my car with my portable oxygen tank and at least one spare. The lift is right outside my door and it takes me to the underground car park where my car is in the closest bay to the door. I'm always breathing a lot heavier by this time but, once I'm 10 minutes into my journey, my sats come back up to about 93-96.

I only work about 3 days a week at the moment. I am usually at the hospital for some test or another one day a week. I try and relax on the other days. I also still try and play golf once a week in my buggy with oxygen attached ... the oxygen only comes off for the shot and then it's straight back on. I still go out for dinner or lunch a couple of times a week as that is one of my great pleasures.

Daily life is very frustrating at the moment, but my attitude is 'onwards and upwards' - one has to be positive. Between Gloria and Dr Jo, I'm in wonderful hands and they certainly help me to keep positive. Next week, I'm off to Papworth for a lung transplant assessment as that's my only hope of survival ... I'm staying focused and positive, and maybe the next time you hear from me, I'll be running a mini marathon ...

**Sadly, Lawrence lost his struggle with Pulmonary Fibrosis on 17th August 2011. He was accepted on to the lung transplant list, but a lung was not available in time.**





## Lung fibrosis and planning a holiday abroad.....Are you fit to fly?

Flying in an aeroplane is equivalent to being 5,000 to 8,000 feet (2500 meters) up a mountain. Think of a mountain twice as high as Ben Nevis, or being a third of the way up Everest. The air is 'thinner' because the pressure is less, and as a result there is less oxygen. In fact, the concentration of oxygen falls from 21% at sea level, to about 15%. Most people will tolerate this alright but, if you already have problems breathing, this will become worse.

**For those patients who do not normally need oxygen:** Patients with lung fibrosis who can walk 100 metres on the flat (equivalent to the length of five London bendy-buses) without needing oxygen, and at a steady pace without feeling short of breath, are very unlikely to have a problem in flight. These patients are considered safe to fly according to the guidelines issued by the Civil Aviation Authority (CAA). If you cannot do this, you should talk to your doctor regarding the safety of travelling by air. They will be able to carry out studies where they simulate the oxygen concentration in the aeroplane cabin. You will be sitting comfortably wearing a close fitting mask that delivers oxygen at the reduced concentration of 15%. They will see what happens to your oxygen saturations over a period of time. They can then recommend whether or not you need oxygen during the flight. Short haul flights are less hazardous than longer ones.

**For those patients that already need oxygen:** Talk to your doctor about how much oxygen you will need in-flight. This may be a higher flow rate than you normally have. You must also remember to arrange oxygen to be available at your holiday destination. Your local respiratory nurses will be able to offer you advice on this.

**For all those patients that need oxygen for the flight:** Remember to let the airline and/or travel agent know in good time, ideally a month before you fly. Some, but not all airlines, charge for oxygen. It is worth planning your flight with an airline that does not charge. Do not rely on the airline having oxygen available at the last minute. The oxygen the airlines carry is for emergencies and would not last very long.

### Final check list once oxygen sorted.....Don't forget:

- Check your insurance policy covers you for medical costs and return home. The British Lung Foundation has a list of insurance companies that will insure patients with lung diseases.
- If going to EEA or Switzerland take an European Health Insurance Card with you [www.dh.gov.uk/travellers](http://www.dh.gov.uk/travellers) or phone 08456062030
- Take a letter detailing your condition and current medication in your hand luggage.
- Take medication with you in your hand luggage, and pack an extra week's worth.
- Arrange disabled assistance at the airport before you depart
- If in doubt, ask one of your respiratory team.

## FUNdraising Tributes and Inspirations

### TRIATHLON MADNESS!



**Thank you to Hayley Bromley** for raising over £100 for research into COPD/bronchiectasis in memory of her godfather who sadly died earlier this year.



Hayley completed two triathlons over one week, seeing her swim 2.25km, cycle 60km and run 15km in total.



### INSPIRATIONS

- ♥ Coffee morning/cake bake
- ♥ Auction of Promises
- ♥ Sponsored skipping
- ♥ Get people to help you quit smoking by fund-raising—a sure way of giving you purpose!
- ♥ Make us your Charity of the Year
- ♥ Join in on any of our events ... or organise one of your own!

### LONDON TO PARIS, JUNE 2012

#### Do you know someone who is up for a challenge?

Breathing Matters would like to get together a team of cyclists for next year's London to Paris bike ride. Do you think you have what it takes?

For more information - Visit [www.londres-paris.com/site/html/home/index.php](http://www.londres-paris.com/site/html/home/index.php)

If you are interested, email us.



**HELP DR JO REACH HER TARGET OF £6k FOR RESEARCH INTO PULMONARY FIBROSIS.**

**EVENTS PLANNED:**  
UCLH Charity Bike Ride  
10K run

**VISIT HER WEBSITE ON**  
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