



## PULMONARY FIBROSIS Support Group Leeds Area

*Compassion, Education and Connection,*

### **Newsletter Number 9 Meeting 25th May 2017 at Stanningley Rugby Club.**

#### **PURPOSE:**

“To provide a welcoming, supportive and informative environment for those affected by Pulmonary Fibrosis in Leeds and the surrounding area.”

There were only 24 people at the Meeting. The Chairman felt it may be as a result of the glorious weather.

He also pointed out that the Committee really needs to change every two years, and that it would be good if others could contribute to the Committee, adding that it is not an onerous task. He asked the members to think about what the Group could be doing that it isn't, and/or could be done better.

APF want to add to the number of Support Groups, currently 41, and would like to double the number. They are also asking for feedback to find out what makes a Support Group successful.

He spoke of the value of the Support Groups. Some weeks ago, Christine and David were in Clinic and met Tony Holmes there. Tony was obviously not at all well, being in a wheelchair and having a large oxygen cylinder with him. Christine spoke to our Chairman about Tony's obvious deterioration, who advised Tony to contact his Co-ordinator straight away. The result was that Tony Holmes was put on the urgent list and was called for transplant within days. As often happens, the lungs were unsuitable for him, but at least the powers that be will be aware of his situation.

Sean Hornby, Mental Health Practitioner. “The Stress Man” spoke about Managing Anxiety.

He said that stress and anxiety go together. He spoke about the causes being particularly difficult for those with respiratory conditions; and that there can be physical and psychological symptoms. He talked about managing the conditions, and said that sitting upright, feet on the ground, straight back, hands on stomach, taking deep breaths in through the nose, holding before exhaling through the mouth, for 5 minutes each day is very therapeutic, but he didn't have enough time to discuss meditation, which he feels is beneficial. He did, however, agree to come again to speak further on the subject.



Information had reached us that Garry Valentine is going to Newcastle for 3 days to be assessed for lung transplantation, so we were not sure if he would be joining us, but he did.

Christine read apologies for absence from Terry and Jo Pearson; Ken and Sue Martin; Ellen Batley; Janet Stocks; Pammi Sahota; Katie Bagshawe.

She had written a letter of thanks to Susan Horsfield, on behalf of her husband, Robert, who is not very well and now housebound. He managed to join us for one meeting which he found beneficial, and enjoys reading the Newsletter, which Christine promised she would continue to send. The letter included a cheque for £50 from Robert, as a donation towards postage, which was much appreciated. Christine had been in touch with Katie Bagshawe, as she had arranged to have an interview with Katie for her dissertation. The arrangement was cancelled due to her University making changes to timetables, etc, so further dates are being considered. Katie asked Christine to display her information again at the meeting, in case anyone else was interested. Katie sent her apologies to anyone she had not been in contact with.

After refreshments, Brian Davies, our Choirmaster, visited us again and we were treated to another singing lesson under his guidance!



**Here's a reminder of our first song.**

Popocatepetl is a big volcano  
Far away in Mexico  
Popocatepetl old  
Popocatepetl goes bang  
Sizzle, sizzle bang!  
So you won't forget that .....  
(back to the top and repeat)  
We also sang "Goodnight Sweetheart".

Our thanks go to Garry Valentine and Kim Ellis, who donated the prizes for the raffle. Winners were Brenda McLoughlin (Meat Platter) and Christine Cole won the (Pamper Package.)  
The raffle raised £46, so thanks also to all our members for their generosity.



Christine told the members of David's recent 80<sup>th</sup> birthday, and invited members to help themselves to the cakes to celebrate this milestone.



**Next Meeting**  
**Date: 27th July 2017**  
**1pm to 3 pm**  
**Speaker:- Dr Tim Sutherland**  
At Stanningley Rugby Club

**Following that: 28th September 2017**  
Speaker:- T.B.A.

Good sites for information are:

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

The British Lung Foundation:  
<http://www.blf.org.uk/Page/IPF>