



PULMONARY FIBROSIS Support Group

Leeds Area

Compassion, Education and Connection,

Newsletter Number 18 **Meeting 27th September 2018 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.”

Ali Husain, as Deputy Chair in place of Imelda Redman, opened the meeting by welcoming the members and outlining the programme for the meeting.

Christine gave the apologies received – Tony and Jackie Gowland, Sue and Ashley Barker, Ann Lockwood, Heather Proctor, David and Sandra Budd.

Professor Louise Wain – Her research will look at the DNA of people with and without IPF as well as those with and without COPD. She will look for genetic differences which might explain why some people develop diseases and others don't and why people's symptoms are different. She will use this information to work out how it can be used to give people personalised treatments. Further information had been found on the internet, indicating that Professor Louise Wain from the University of Leicester and Professor Gisli Jenkins from the University of Nottingham, also Researcher for APF, were lead authors of the study. The work was led by researchers at Leicester and Nottingham and brought together collaborators from around the world to form the largest combined analysis of people with IPF undertaken to date.

Steve Jones, Chair of APF, said: “This is important research, which will give hope to the 33,000 people in the UK living with IPF and their families. We need more research like this into the genetic factors underlying the disease and possible treatments.”

Christine spoke about our donation to British Lung Foundation for a specific research project. The committee had considered two projects with a leaning toward the one which appeared to be specifically aimed at IPF, but further information has since been discovered, and members were invited to vote for the preferred research project.

Professor Toby Maher – Research will focus on finding ways to improve outcomes for people living with IPF and to find out more about the biological mechanisms that cause lung scarring. His research will identify groups of individuals who may respond to personalised treatment, identify better ways to measure changes in lung scarring and to improve clinical trials to test new IPF treatments. It will also develop ways to monitor patients so we can detect and treat life threatening infections as early as possible.



A show of hands voted in favour of the first project, by 13 votes to 11.

Professor Louise Wain

Our Speaker was Tom Harris, of Carers Leeds, who informed us about their services, and ways in which they can support carers. These include Carers Support Groups, a Drop In service at their central Leeds Office, one-to-one support on a number of concerns. They also give advice on how to access welfare benefits, respite care, sitting services and many others. The website is Carerstrust and we were assured that Support Groups for Carers are available for help in most towns.

The carers advice line in Leeds is 0113 380 4300.

Tom Harris –Carers Leeds



Val McNaughton was available to take names and money for the Christmas meal, arranged for Thursday 6th December, at 12.00 noon for 12.30 pm, at the Cornmill Hotel & Restaurant, on the Leeds Ring Road, as in previous years.

Christine also informed the members about a Yorkshire Patient Information Day at Holiday Inn, Doncaster, on the 22nd October 2018. The programme for the day had been emailed to members who had access to the internet, and had some copies available for those who did not. Our members said they were having difficulty getting through on both the link email and the telephone number.

Christine will make enquiries.

Once again, thank you to all our bakers for their generosity, and to those who gave prizes for the raffle, which raised £63.00; donations on the door raised £110.



Emma Baylin

Singing for lung health leader.

Emma Baylin, “Cherished Harmonies” then gave us a taster session of what happens in her singing groups. Emma is supported by the British Lung Foundation. She has been running her class in Halifax (at the Old Crossleyans Rugby Club) for 3 years, and has up to 20 members. She is currently trying to secure a venue for a group in Leeds,

She began with a relaxation session, which was VERY relaxing, followed by some short scales and exercises. We then began the singing and Emma taught us three short songs which, after the initial teaching and practising, the Group was split into two and we sang in “round robin” style and, eventually, harmonising! It was great fun and the members really enjoyed themselves. Two people spoke to me at the end of the meeting, saying they are really interested in attending Emma’s group in Halifax! A good result!

STOP PRESS:

Speaking to Sandra Budd later by telephone, she tells me that their Granddaughter, Crystal Taylor, and their nephew Peter Doogan will be raising money this year by doing a parachute jump on 25th October 2018. They are to open a Just Giving page and £200 of the proceeds will go to St Gemma’s, the rest to APF. You may remember that two years ago, Peter climbed Mount Kilimanjaro to raise money for APF.

Good sites for information are:

Action for Pulmonary Fibrosis:

<http://>

www.actionpulmonaryfibrosis.org/

The British Lung Foundation:

<http://www.blf.org.uk/Page/IPF>

Next Meeting
Date: 29th November 2018
1pm to 3 pm
At Stanningley Rugby Club
Speaker:- Dr. Paul Beirne
Consultant Respiratory Physician.

Following that: 31st. January 2019