



PULMONARY FIBROSIS Support Group

Leeds Area

Compassion, Education and Connection,

Newsletter Number 10 **Meeting 27th July 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.”

In the absence of our chairman, Tony Gowland, Christine welcomed the members and gave the apologies of those unable to join the group – Tony and Jackie Gowland, Terry and Jo Pearson, Andrew and Ivy Learmonth, Geof Symons, Angela Ward and Tony Holmes.

The Group was informed of the passing of Pammi Sahota, Ellen Batley and Katie Bagshawe’s father. We were delighted to see that Katie and her mother were at the meeting, and they were made welcome.

Christine also gave updates of Tony – still at the Freeman Hospital, Newcastle, but improving; Terry at home but using oxygen 24 hours and has recently developed Shingles. She also explained the further developments of her own health problems (Vasculitis) and new medication – steroids, and low level chemotherapy at 3 week intervals, rather than Nintedanib for her IPF. She explained that she was feeling very well under the new treatment.

Christine had been asked by Bev Wears, from the British Lung Foundation, to inform the members of a BLF Personal Organiser, available online, and had taken a sample for people to see.

Good sites for information are:
Action for Pulmonary Fibrosis:
<http://www.actionpulmonaryfibrosis.org/>
The British Lung Foundation:
<http://www.blf.org.uk/Page/IPF>



As a result of Christine’s “plea letter” our members came forward to volunteer help, thanks in some cases to David’s efforts on the door, catching people as they arrived! We were delighted to receive offers of help from Kim Ellis as Treasurer, Val McNaughton and Jan Kirby for Refreshments, Sandra Husain will take on Fundraising, and she has a friend who may be willing to assist with secretarial work, and Heather Proctor will sign people in on the door and give out badges. We are also grateful to Jane Slough, who had also brought a work colleague, Ann Lockwood, a Respiratory Nurse who is taking retirement, and who is willing to become involved, too.

Dr Tim Sutherland Consultant Chest Physician from the Leeds Interstitial Lung Disease (ILD) Service talked to the group about the Leeds ILD Service.

He explained that with in the Leeds clinic, patients with a wide range of interstitial diseases are seen including idiopathic pulmonary fibrosis (IPF) as well as a number of other rarer interstitial lung diseases. The Leeds ILD clinic assesses patients initially in a dedicated new patient clinic and performs various tests which usually includes lung function and full blood screen. As well as having full multidisciplinary team (MDT) discussion including doctors, nurses, specialist x-ray doctors and pathologists when making a diagnosis. The service also provides follow-up and initiation of treatments.

The Leeds ILD service provides local service to around a population of 751,000 as well as a tertiary service (specialist care) to West and North Yorkshire for a population of around 3.5 million.

Dr Sutherland highlighted some of the changes that have happened within the service for the last seven years.

- 2010 - ILD nurse specialist role established
- 2011 - Enrol IPF patients into clinical trial for first time (one of 8 UK centres participating in IN PULSIS trial)
- 2013 - Recognised by NHS England as a pirfenidone prescribing centre 'commissioned'
- 2013 - Appointment of second consultant with interest in ILD coincident with doubled workload
- 2014 - Established role for ILD MDT coordinator as ILD MDT referrals from across Yorkshire double, and MDT meets weekly
- 2014 - Patient access scheme for pirfenidone
- 2015 - Patient access scheme for nintedanib
- 2015 - Host first meeting of Northern ILD Network
- 2015 - First IPF support group meeting!

The raffle raised £82. Garry Valentine donated his usual meat platter, won by John Millsop, and Brenda McLoughlin a bottle of wine, won by Sally Small.

A good selection of cakes had been donated, too.

Donations at the door amounted to £104.

Thank you to all for their continued generosity.

Next Meeting

Date: 28th September 2017

1pm to 3 pm

Speaker:- TBA.

At Stanningley Rugby Club

Following that: 30th November 2017

Speaker:- Ian Borrows—Baywater Oxygen.



Data was presented showing that in 2016 to 2017 the service saw 400 new patients and over 2000 follow-up appointments. It was interesting to see that in July 2013 they saw 89 patients compared to 454 in July 2017.

Dr Sutherland explained what the NICE Quality Standard 79 states what is expected for patients with IPF.

People are diagnosed with the consensus of an MDT

People with IPF have a specialist nurse available to them

People with IPF have an assessment for home and ambulatory oxygen therapy

Pulmonary rehabilitation programmes provide services that are designed specifically for IPF

People with IPF and their families/carers have access to services that meet their palliative care need.

There was a lot of discussion within the room about shortfalls and variation in the current service provision. Dr Sutherland highlighted that the Leeds Service is working to try to develop pathways to develop services closer to home as well as generally raise the profile of IPF. He mentioned having a focus group to discuss ideas we may have about how to change the situation, which everybody thought was a good idea.



Christine thanked those people who had volunteered to help with the Group. Val and Jan are also prepared to organise another Christmas meal – to be discussed at the September meeting.