



PULMONARY FIBROSIS Support Group Leeds Area

Compassion, Education and Connection,

Newsletter Number 17 Meeting 26th July 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.”

Imelda welcomed everyone to the meeting and thanked everyone for all the generous raffle prizes which had been given today. It was agreed that some of the prizes be kept back for the next meeting in September.

Date for the Christmas Party was announced, Thursday 6th December 12.00 noon at the Cornmill Restaurant.



The Meeting started with a light lunch of sandwiches, crudités, sausage rolls and some delicious pork pies, kindly provided by Val, which were a real winner! Delicious cakes and shortbreads were made by our members and very much appreciated.

Steve Jones - Chair of APF Trustees, attended the meeting to receive a cheque for £2000 from the group, give a short talk about APF and how the Group's donation of £2000 would be put to

In relation to research, APF aim to support projects which improve care understanding, treatment and support for people with IPF. The applications for the Mike Bray Fellowship Award have been narrowed down to 3 and are inspected by scientists and other experts in the field. Steve reported that there is some ongoing research by Galapogus which is looking into drug combinations to break down 1 or more of the processes that lead to lung fibrosis. He agreed to come back at some point in the future to give an update on the progress of the research projects.

APF has now been established for 5 years and has a number of services established:

IPF telephone support line, this is particularly useful for patients outside the specialist centres who may not have access to specialist nurses through their medical consultant.

Training for GPs and Nurses in General Practice in how to recognise and differentiate IPF with an emphasis on early diagnosis.

They are trying to increase the number of support groups accessible for people with PF and the aim is for all patients to have a support group within an hour's drive.

There is a commitment to raise awareness about what IPF is. There is some TV coverage planned in the near future to question the 80% rule which applies to the prescription of anti fibrotic medications and to highlight the lack of a defined care pathway for IPF, as there is for Cancer, Heart Disease etc.

Pam Harcourt, a former Tiller Girl came to talk about “What she did for Kicks”

Pam Harcourt gave a fascinating and very entertaining account of her life from joining the Tiller girls at age 16 to her last performance in 2008, live on The Paul O’Grady TV show.

The Tiller girls were best known for their high kicking routine and performances on Sunday Night at the London Palladium.

Pam described the highs and lows of life in the troupe as Head Girl and the unpredictability and unsuitability of some of the accommodation they were given whilst at summer seasons away from London or on tour. She recalled one memorable performance at The Savoy hotel at a function for Lady Harewood where Princess Margaret was also a guest.

Pam did a huge jumping split and landed under a table in front of the stage.

Pam circulated photographs of her and the rest of the troupe at points during her talk to give an impression of the costumes they wore, and the makeup and headdresses.

Pam was given a hearty round of applause after a very enjoyable session.

Attendance was 44 people.

Apologies were received from:- Pat Armitage, Steve Day, Sally Small, Jo Pearson, David & Sandra Budd.

Donations at the door were £135



Next Meeting

Date: 27th September 2018

1pm to 3 pm

At Stanningley Rugby Club

Speaker:- Tom Harris –Carers Leeds & Emma Baylin –Singing for breathing

Following that: 29th November 2018

**Speaker:- Dr. Paul Beirne
Consultant Respiratory Physician.**



Formed by John Tiller in Manchester in 1889, the first dancers performed as ‘Les Jolies Petites’

He had noticed that the chorus dancers were often spoiled by poor discipline, but when they linked arms, they danced as one..

Famous for their high kicking routines, The Tiller Girls were highly trained and precise.



The raffle raised £84.50.

Prizewinners were:-

Stan Boam, Barbara Boam,,
Tony Gowland, Imelda Redman,
Ali Husain, Mandy Stead, John Collier,
Mavis Reed, Fred Galbraith
& David Cole.

Good sites for information are:

Action for Pulmonary Fibrosis:

<http://>

www.actionpulmonaryfibrosis.org/

The British Lung Foundation:

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