TAMESIDE PULMONARY FIBROSIS SUPPORT GROUP

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AUGUST NEWSLETTER

ANGELA ROBBINS & ANDREW WILLIAMS – TAMESIDE ROTARY

We were very lucky to have Angela, who is the District Environment Officer, and Andrew on our July Zoom meeting. Angela is always very busy (I don`t think she sleeps) so it was good to see her sat down for an hour or so to talk to our group.

Rotary was formed in 1905 by Paul Harris, a Chicago Attorney, so professionals with diverse backgrounds could exchange ideas and form meaningful, lifelong friendships. They started by having lunch at each other`s place of work – hence Rotary rotating.

They raise money by holding the annual Beer Festival in Stalybridge, the Santa Float which travels around Tameside collecting donations, Fashion Shows, and Concerts to name just a few. We are very lucky to be supported by Rotary Tameside, who have given us many Community Cash Awards over recent years. We appreciate their support, and it really does make a difference. We use the money we are given to pay for the `chippy run` trips on the Canal Boat every month.

TPFSG CANAL BOAT TRIP

It was another enjoyable canal boat trip in July thanks to East Manchester Community Boat Project providing these trips for us. Barbara and our Volunteer Ange were the Comrades on board this time. The crew was Eddie, Graham, and our very own Comrade Ship`s Captain Sue Steventon.

As usual, it was the chippy run, and all food was paid for by TPFSG. We can do this because our amazing Barbara applied for funding and was successful, therefore we can pay for the food on all the trips this year.

Our August boat trip is fully booked, but if anyone can`t make it on the trip, I will let you know if you have expressed an interest in coming along on one of the trips.

Duchy of Lancaster

Action for Pulmonary Fibrosis

Happy to Support TPFSG

Dr John Blaikley – Wythenshawe Hospital

Dr Blaikley is a Consultant Researcher at Wythenshawe. He asked if he could come along to our Zoom meeting to tell everyone about Home Monitoring for ILD. He talked about how some patients progress quickly while others progress slowly. Treatment for PF is available but will only be prescribed once the disease starts to progress.

Lung Function can be done at home, but by itself it isn't good at showing disease progression. Patients can usually tell for themselves if they are feeling better or worse.

There will be a feasibility study to ask will it work? Is it acceptable for patients? Does it work in practice? The study will take place over three years.

Patients will still be observed at hospital every 6 months regardless of home monitoring outcome.

FACE TO FACE MEETING

We held our July F2F meeting on Friday 17th July. It was a very busy meeting with over 60 people attending. We have always joked that we might have to start considering the Manchester Arena if we get any bigger. Suppose I had better look for the phone number for them.

We welcomed ILD Nurse Katie Zakis from Wythenshawe Hospital to group. She talked to everyone, giving good advice and listening to everyone`s concerns too. It is good to have regular visits from the Nurses, as it means you can ask questions, and they can see what is happening within the group.

We also had a visit from Laura Roberts who is from Home Instead, who provide home care to help people stay independent and comfortable at home. If you would like any information you can look on the website www.homeinstead.co.uk Laura said she really enjoyed being at group and was made to feel vey welcome by everyone.

Matthew Pritchard from the Medicines Evaluation Unit came along too. He came to talk to everyone about research and what the MEU can offer by way of trials. If anyone is interested in finding out more about MEU and trials, their website is www.meu.org.uk

We are always very grateful to our volunteers who help out at the meetings by setting up the room for us, and those who make the tea/coffee and serve the food. It really does make a difference and gives the Comrades time to talk to everyone. Thank you for giving up your time to come and help us.

PULMONARY FIBROSIS TRUST – CARAVAN HOLIDAYS

The PF Trust have a caravan that patients and their families can use. It is located on the Haven Seashore Caravan Park in Great Yarmouth, Norfolk. The park has numerous facilities for all the family including a water park, amusement arcade, bars and restaurants, shops and lots of entertainment, all of which you will be able to access. There is direct access to the beach, but if you do want to go further afield Great Yarmouth is nearby.

The caravan has three bedrooms (sleeping six people), and two toilets. It is double-glazed and has central heating for cooler days. There is a fully equipped kitchen and linen is provided. There is a small fee of £25 per night to cover cleaning and site fees. Outside the caravan there is a nice decking area for sunny days and a ramp, so everyone has access. Passes are also provided which entitle the holder to a 15% discount on all on site purchases.

RSV VACCINE OPENED UP TO MORE PEOPLE

NHS ENGLAND have released the following information about the RSV Vaccine:

`Thousands more people at risk from a virus which causes pneumonia and other serious lung infections will be able to get vital protection on the NHS this winter.

From September, all adults aged 65-74 who are living with a chronic respiratory disease, and those with immunosuppression due to disease or treatment will be offered the respiratory syncytial virus (RSV) vaccine, as the NHS expands its life-saving programme to protect those who are most vulnerable.

Eligible people will be able to receive their jab from their local GP practice or, in some parts of the country, at their local high street pharmacy from 1st September, to protect themselves from serious illness and hospitalisation.`

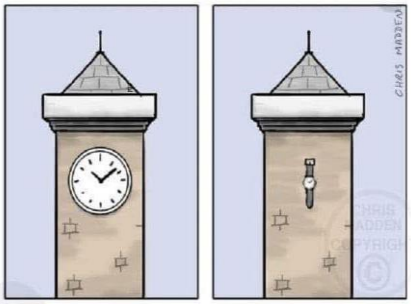
BIRTHDAYS

We have 2 birthdays coming up in the next month, up to the next zoom meeting. We wish you both a very Happy Birthday and hope you each have a wonderful day!

Sue McG

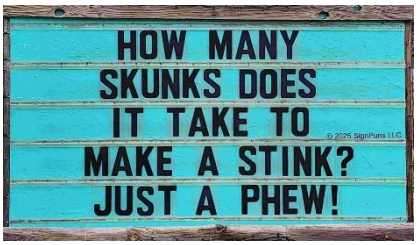
Phil B

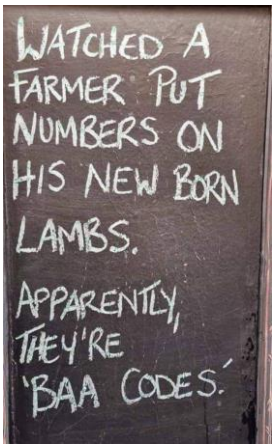
And finally . . . Don't forget, laughter is the best medicine



Little Known Fact:

Richard Gere`s dad, Gottler, was a famous Swedish ventriloquist!





A man was given the job of painting white lines down the middle of the road.

On his 1st day he painted 8 miles, on his 2nd day he painted 3 miles, and on his 3rd day he painted 1 mile.

The boss wasn't pleased. He asked, "why is it that you are painting less each day?"

"Because each day I get further away from the can of paint."

The next face to face meeting - 21st August 12.30 to 2.30pm

Next zoom meeting - 2nd September at 2pm

BARCHESTER'S CHARITABLE FOUNDATION
Making a difference

action together

Williams Deli

Happy to Support TPFSG