



TAMESIDE PULMONARY FIBROSIS SUPPORT GROUP



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APRIL NEWSLETTER

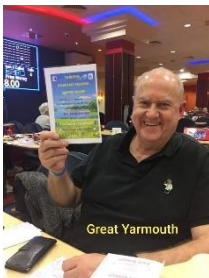
ROGER GLADWELL



We received the very sad news on Friday 27th March that Roger has passed away. His son Andrew said he died peacefully.

Roger has been a part of TPFSG for a long time. Clive had been giving one of his talks to a group of people and Roger was one of the people there. He decided to come along to one of the groups after that. I remember when he first came, I asked him if it had been beneficial to him. He said he `wasn't sure if it was for him,` but he must have decided it was, because he came regularly to our face to face meetings, and joined the zoom meetings when he could too. Roger enjoyed the canal boat trips that we have every month from April to October. He was always our `go to man` if we ever had a seat available too. We will miss Roger very much. He was a lovely, gentle man.

PETER BRYCE - PF TRUST



We invited Peter Bryce to talk about the PF Trust at our March Zoom meeting. It is always a real pleasure to listen to Peter.

The PF Trust was started by three people and Peter joined in 2014. In 2016 he became a Trustee and then took on the role of Chair. As a Trustee you can be held personally liable for the actions and debts of the charity. The Trust has recently become a Charitable Incorporated Organisation which means the Trustees are not liable for the Charity`s debts if ever there are any.

The Trust does amazing work for people with PF. Many of our Support Group have benefitted from the help given by Peter and the charity. From mobility scooters, to wheelchairs, to stair lifts. The Trust has provided them all. If you need help with any of these items, please go to their website www.pulmonaryfibrosistrust.org and complete the form or give them a call on **01543 442 191**.

ACTION FOR PULMONARY FIBROSIS

In June 2025, APF carried out a `State of the Nation` survey with regard to Pulmonary Fibrosis. Questions asked covered things such as delays in diagnosis, mis-diagnosis, access to pulmonary rehabilitation, access to specialist centres to name but a few. The Report has now been published after several delays, and it is grim reading.

We know from current members, and the members we have had at TPFSG over the years, that the problems of diagnosis, accessing treatment, pulmonary rehabilitation, and palliative care, can be extremely difficult and delayed, sometimes not even happening at all.

These are some of the figures published:

- The percentage of people waiting more than 6 months for a diagnosis was 48%, and 34% waited for more than a year.
- 90% of respondents reported experiencing multiple PF symptoms before diagnosis.
- 65% of people in England were subject to multiple appointments with their GP before being referred to a specialist.
- 19% of patients reported not having received a referral to palliative care at all.

Daniel Saxton, APF Chief Executive Officer said ***“this report does more than expose the issue; it calls for immediate change. To the NHS, government, clinicians and everyone who shapes services, our community is ready to work with you. We need you to move faster and to show that change is happening. Lives depend on it.”***

You read the full report by going onto the APF website www.actionpf.org and in the `about us` section click news and it will take you to the report.

APF WEBINARS AND PODCASTS

- An Introduction to Navigating the PF Journey - **Wednesday 15th April, 3 – 4pm**. This is a repeat webinar for people wanting to learn more about Pulmonary Fibrosis.
- Talking PF: Adapting to living with oxygen - **Wednesday 20th May, 3 – 4pm**
APF`s panel of experts discuss practical aspects of living with oxygen.
- Breath of Hope: Pulmonary Fibrosis Stories - APF`s new podcast series.
Hear from a range of expert members of APF`s team and people affected by PF.

FACE TO FACE MEETING



The March Face to Face meeting was another busy one. We were due to have Andy Ball from the Fire Service, to talk about his work with the Scent Detection Dogs. Sadly, on his way to us, he was called to a job so had to postpone. We will arrange a different day for him to come along.

Once again, we had potato pie and cheese and onion pie, (plus the usual sweet treats etc) at the meeting. The pies were made by Sizzlers in Stalybridge and went down very well. We are 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.

FIREGROUND MUSEUM TRIP

On Friday 27th March, we had another trip to the Fireground Museum in Rochdale. Thanks to funding organised by Barbara for the whole trip, we were able to hire a minibus, which took us there, and paid for lunch in the Fireground café too.

We had a guided tour with Les, one of the retired fire service personnel who volunteers at the museum. He even let Kath dress up as a Firefighter and sit in one of the engines. We were very well looked after by everyone.



BIRTHDAYS

We have 8 birthdays coming up in the next month, up to the next zoom meeting. We wish you all a very Happy Birthday and hope you each have a wonderful day!

Ian

John

Melanie

Charlie

Kath

Barbara

Betsan

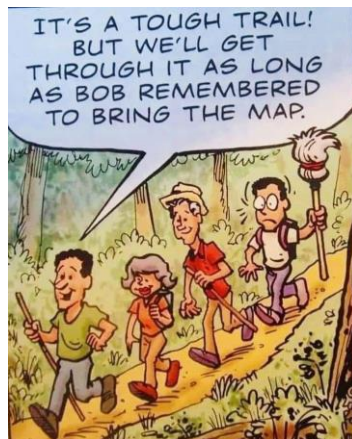


Happy to Support TPFSG



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

I tried to walk like an Egyptian and now I need to see a Cairo practor.



A policeman stopped me and said: "Would you please blow into this bag sir?" I said: "What for officer?" He said: My Chips are too hot." (Tommy Cooper) 😊



Books that were never written:
"Running to the Outhouse" by Willy Makit. Illustrated by Betty Wont.



Dave says to Fred "Have you heard the news? 3 Cliff Walkers have fallen to their deaths!" "Unbelievable, says Fred. I can't believe they all had the same name!"



Boss, there's someone here trying to pay with his phone!

Wanted: Someone to brush their teeth with me because 9/10 dentists say brushing alone won't help tooth decay. No weirdos please.

The next face to face meeting - 17th April
12.30 to 2.30pm

Next zoom meeting - 6th May at 2pm



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