TAMESIDE PULMONARY FIBROSIS
SUPPORT GROUP

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JANUARY NEWSLETTER

SO, THAT WAS CHRISTMAS!

Welcome to 2026!

We hope you had a lovely Christmas and enjoyed doing whatever makes you happy! We would like to wish you all the very best for the coming year, and we hope it will be kind to us all.

At our Christmas Zoom meeting we decided not to have a Speaker, but to have a Quiz, hosted by our lovely Comrade Raffler Mo, and after we had exhausted our knowledge (or lack of it) we just chatted among ourselves. After the meeting, I was able to send `One 4 All` gift vouchers to our quiz winners and to members too. Thanks to Barbara getting lots of funding for us over the past year, it has meant we have been able to do this in the summer, and again at Christmas. Over 2025, Barbara applied for and received funding of £4904.29, which means we have plenty to keep us going for quite some time.

ILD NURSES ZOOM MEETING

Wendy Jones was the Guest Speaker at the zoom meeting. She talked about APF and what we can expect from them in regard to help and information.

It was mainly general chat among members and requests for information. Someone asked about how often a patient should have a lung function test. Jenna (ILD Nurse) said that LFT`s are usually performed every 6 to 12 months, depending on the patient and how their PF is progressing, but if necessary, a patient can be contacted to have an earlier LFT appointment.

Perfenidone - patients mentioned that whilst taking pirfenidone they have noticed they have itchy skin and wondered if there was anything they can do to relieve it. Camomile creams were suggested as were anti-histamines. Before taking anything though, it is best to check with your ILD team and your GP about any interactions with other drugs you may be taking. Also, if using oxygen, check that creams can be used safely, and aren`t oil based or paraffin-based creams.

One of the topics mentioned at the zoom was the difficulty in finding a parking space at Wythenshawe hospital if called in for a face-to-face appointment. In Tameside we are lucky to have organisations who for a small fee/donation will pick you up from home, take you to the hospital, and bring you home again. If you are struggling with getting to appointments, it might be worth looking to see if there are organisations in your area who will help you in a similar way.

COMMUNITY FUND

ASDA

Action for Pulmonary Fibrosis

Happy to Support TPFSG

ACTION FOR PULMONARY FIBROSIS

In December I joined a zoom meeting with APF which included the Chief Executive, Daniel Saxton. The meeting was about the 5 year Strategy that APF have, and about what we would like them to do for PF patients and their families over the coming years.

The Support Line has become more popular and is manned by people with experience of PF and by Specialist Nurses. Online and Chat versions of this have been discussed and will be considered. The general consensus was that people prefer to speak to someone, but for some people, this can be quite daunting, so to have an online/chat version might be helpful. Many people I speak to say that it would be good to have a Support Line in the evening and at weekends, because PF isn't a Monday to Friday, 9am til 5pm disease, so I brought this up at the meeting and asked them to consider it.

Someone mentioned the lack of information on social media. There are lots of posts celebrating peoples` achievements at raising money, but when it comes to useful information, for instance how to cope in very cold weather, or how to get help with benefits, there isn`t enough.

The usual subject of mis-diagnosis and delays in diagnosis came up, and we asked for APF to work at changing this because it happens far too often. Working with GP`s and Healthcare Professionals, and medical students is something that would help.  I mentioned about how Clive and I talked to our GP Surgeries, and Clive talked at an event for all Tameside GP`s, and how Barbara will be talking to a Patient Participation Group at a GP surgery in Ashton this month.

In the summer of 2025 APF carried out a survey among the PF Community. Sadly, the results of this survey are still not being made available and may not be available until February at the earliest.

PULMONARY FIBROSIS TRUST

Most of you will be aware that the PF Trust provides practical support to PF patients. You can contact them to help with the supply of stair-lifts, mobility scooters, wheelchairs, and additional batteries for portable oxygen concentrators. You can apply for funding either by completing the form on their website at **www.pulmonaryfibrosistrust.org** or by phoning **01543 442 191.**

The PF Trust also has a caravan at the Haven Seashore Caravan Park in Great Yarmouth. As a PF patient you can stay at the caravan for a fee of £25 per night. You can choose between a long weekend, a four day mid-week, or a week-long break. The caravan sleeps 6 so you can take family and/or friends with you. For more information, go to the website or telephone them (same details as above).

The PF Trust has helped many of our support group members and we appreciate everything that Peter Bryce and his team do.

Pulmonary Fibrosis Trust

TESCO

Greenfield

healthwatch Tameside

Happy to Support TPFSG

FACE TO FACE MEETING

On 12th December we had our Christmas Face to Face meeting. We had the pleasure of the company of Nigel Anderson, Co-Founder of the East Manchester Community Boat Project. He came along and entertained us with some of his `true` stories, and we thank him for taking the time to come and do that for us.

It was lovely to see Wendy Jones from Action for Pulmonary Fibrosis at our meeting, and Steph Fitton from Stalybridge and Dukinfield Rotary, who continue to support us. We very much appreciate their support.

We had lots of raffle prizes at the meeting, the top prize being a Ninja Foodie – a slow cooker – donated by Holly and Benn, plus prizes including a hamper (also donated by Holly and Benn), and two hampers donated by Richard and Natasha Maines who have a small business called Maid Maines. We also had a TPFSG Tombola, where everyone was given a free raffle ticket and during the afternoon we pulled the tickets and everyone went home with a gift.

The wonderful buffet food was supplied by S. Williams & Sons, who are based in Ashton under Lyne market. Food left over at the end of the afternoon was shared between members, and some food was taken by one of our members to be distributed to the homeless people in Ashton.

TPFSG WEBSITE

We now have a TPFSG website, with information, links to organisations, and our Around the World photos. Take a look at www.tpfsg.co.uk and let us know what you think, and what you would like to see on there.

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!

Anita

Benn

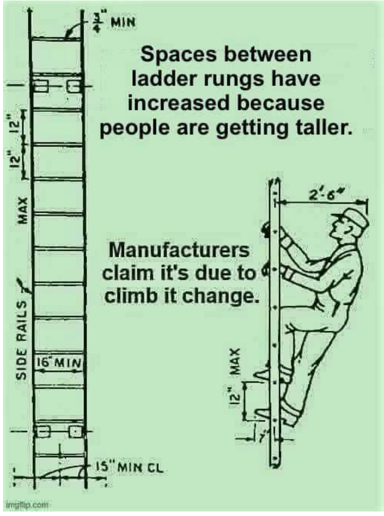
Dukinfield and Stalybridge Rotary Club

action together

Pennine Care NHS Foundation Trust
BE WELL TAMESIDE

Happy to Support TPFSG

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



Spaces between ladder rungs have increased because people are getting taller.

Manufacturers claim it's due to climb it change.

I keep having the same dream, where I'm a horse

That's 5 nights on the trot ... 🐴 😂

The missus asked what I was doing on the computer.

I said I was looking for cheap flights...

She got all excited, which is strange as she's never shown any interest in Darts before!

Having lifted all my Dusty Springfield LPs up into the loft, I just don't know what to do with my shelf....

What do you do for a living?

I'm a spy!

Why are you dressed like a shepherd?

I'm a shepherd's spy!

FOR SALE
90S ICONIC SOOTY AND SWEEP PUPPETS
ANY OFFER ACCEPTED
JUST WANT THEM OFF MY HANDS

The next face to face meeting - 23rd January 12.30 to 2.30pm

Next zoom meeting - 4th February at 2pm

BARCHESTER'S CHARITABLE FOUNDATION
Making a difference

ASDA

Rotary Tameside

Happy to Support TPFSG

A Year in the Life of TPFSG

And what a year 2025 has been! There have been some very low times, but some positive times too.

In 2025 we lost 9 of our members, including my beloved husband, our El Presidente, Clive. Every loss is felt deeply, but for me this year, none more so than losing Clive. Without Clive, there would have been no PF Support Group. It was back in 2018, after visiting the Wythenshawe Hospital Support Group, that he decided we needed one in Tameside because getting to Wythenshawe isn't the easiest, and their meetings were only held once every two months. Clive felt that we needed to hold meetings every month, so that friendships might blossom and we would be able to help each other. He was right, friendships have been made, and a network of information passed from one member to another, making living with PF a little more bearable. So in April 2018 TPFSG was launched. Clive has left quite a legacy behind, and I, along with my family and our wonderful Comrades, will continue with it for as long as our health (and age) allows us to.

As you know, we not only have the face-to-face meetings, we also hold zoom meetings every month. We also have our canal boat trips between April and October, provided by the wonderful East Manchester Community Boat Project, of which our **Comrade Ship`s Captain Sue Steventon** is Co-Founder, along with Nigel Anderson. The `Chippy Run` is a wonderful few hours sailing along the Peak Forest canal, chatting with friends and eating good food, which this year has been paid for by TPFSG, after our amazing Comrade Fundraiser, Barbara Evans, applied for, and successfully received funding to cover all the expenses.

Speaking of **Barbara**, she is a woman on a mission. If there is funding to be had, Barbara will find it, apply for it, and nine times out of ten, will be successful in acquiring it. Over 2025 she managed to get funding for our group totalling £4904.29. This money pays for the hire of the room, food at each face-to-face meeting, buffets at the April Anniversary meeting, and at the Christmas meeting, food for the boat trips, and we have trips to the Fire and Police Museums to look forward to in 2026. There is also the ongoing costs of the monthly Zoom meetings, stationary, printing, phone rental, and we have bought two re-furbished phones for Barbara and Helen so they can receive and make calls without having to use their own phones, plus we now have a website – take a look at www.tpfsg.co.uk.

When Clive and I set up the group, we never expected it to grow and develop the way it has, and over recent years we have the Comrades to thank for being there and playing a big part in doing that. They have made such a big difference to our group. For those of you who come along to the face-to-face meetings, you will be aware that we now also have several volunteers who help us with serving drinks and food and they help us to set up the room and clear away again at the end. They are a great help to us, and we appreciate them giving up their time to come along.

There have been a lot of events over the year where we have been able to raise awareness of PF and our Support Group. They have been attended mainly by **Barbara and Andy**, and I am starting to get back `on the circuit` slowly but surely. **Mo and Helen** have attended Rotary events to receive cheques on behalf of TPFSG for grants awarded after (yes you guessed it) Barbara applied for funding. In September alone, between us, we attended 15 events as well as the usual meetings.

Sue Turner has again been helping members to claim Attendance Allowance, something she has been doing since the early days of TPFSG, and it can make such a big difference to everyday life, helping to pay for a cleaner or a gardener, and just making things a little easier generally. Someone worked out how much these claims over the years will have been worth, and the amount is outstanding, well over a million pounds for our members. Sue is definitely worth (a lot more than) her weight in gold.

Over the year we have had several speakers on our zoom meetings and guests at our face-to-face meetings too. From the ILD Nurses, to GMP Scambusters, to Estate and Planning, and Oldham Mountain Rescue. We certainly have a varied selection of speakers. We hope you enjoy the variety, and if there is any topic you would like to hear about, (keep it clean), please don`t hesitate to let us know.

We have had several publications over the year too. The interview Clive and I took part in with Bev Bryant at ALIAD – A Life in a Day – was aired and the blog that she wrote was published. There were publications in the European Lung Foundation magazine, APF`s Insider Magazine, NARF – National Association of Retired Firefighters - Tameside Reporter, About Tameside, Tameside Correspondent, and plenty more on social media platforms too. Its been a busy year!

One thing I wasn`t expecting to happen in 2025, was being told **Clive and I** had been nominated in the Greater Manchester Health and Social Care Awards, and that we were finalists. Sadly, Clive never knew about the nomination as I didn`t find out until May and as you know Clive passed away in March. Along with my daughter, son, and several of the Comrades, I went to the awards night in July at the Museum of Science and Industry. To my surprise, Clive and I won our category, Community Champion. It was a very bittersweet moment – feeling very proud that we had won, but very sad that Clive wasn`t there by my side to receive the award. I know he would have felt proud and honoured to receive it.

Around the World with TPFSG has continued to grow too. We have received many photos from members, family, friends and even people we don`t know but who have been given a poster by someone else. We hope that in 2026 we will receive many more and maybe even from famous faces. So, if you are going on holiday, or a day trip, or you just want to take a photo in your garden, please send us as many photos as you want to, we are always happy to receive them and it raises much needed awareness because I share them on all our social media platforms and now on the website too. If you (or someone you know) are going to the theatre or to a music event, or you just know someone famous, ask for a photo, and please tell people, it will cost them nothing but two minutes of their time, but will mean a great deal to our Support Group and to the PF Community.

Finally (I promise), I would like to say a big thank you on behalf of myself and all our Comrades and Volunteers, to everyone who comes along to group, or joins our zooms, because without you there would be no group. Also, to those who come to speak to us, or provide us with information, we appreciate you giving up your time to help us and your continued support means a great deal to all of us at TPFSG.

To everyone who has this dreadful disease, you are the bravest people I know, and I wish you all nothing but the best, for you and for those who love and care for you.
With my love and admiration for you all, Sue G. xx