

Support Group News



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Feature story

New APF website goes live!

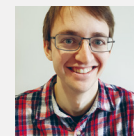
We asked you what would make the biggest difference to your daily lives. You told us that specialist, up-to-date and accessible information was a top priority. Our new website is just what you asked for. It has over 70 pages of information, advice, personal stories and details of all support groups across the UK.

We've also included a Coronavirus Hub, where you can find all you need to know about the virus and ways to support yourself and loved ones whilst in self isolation. The hub is constantly updated as information, advice and knowledge changes.

Becca Thomas, APF Digital Communications Specialist, said: 'We will be working hard to keep improving the content and design of the website so that everyone can feel empowered with the right information. Please take a look at www.actionpf.org and tell us what you think. And let us know if we've missed anything!' If you have feedback do get in touch at info@actionpf.org

'Fresh and dynamic. Better than we ever expected.'

'All I can say is, wow!'



**Live webinar:
does DNA
hold the key to
understanding IPF?**

APF-funded Mike Bray Research Fellow, Dr Richard Allen, led the largest genetic study of idiopathic pulmonary fibrosis to date. He'll be bringing his findings to your living room in September via a live talk on the genetics of IPF. 'We know that DNA can change how at risk a person is to certain diseases, including IPF. I will describe how we use DNA to identify processes that increase the risk of IPF, and how we can use this information to help develop much needed treatments.'

When:

2 September 2020 at 8pm

Register in advance with Zoom:
[actionpf.org/news/webinar](https://www.actionpf.org/news/webinar)

Welcome



This very challenging time during the Covid-19 crisis and shielding has, strangely, generated new opportunities to connect and support each other. Regional Support Coordinators Jo Ruck (north) and Gillian Trippner (south) are busy getting to know you, including through the leaders' Zoom meetings. And our first Telephone Support Ambassadors are reaching out with a friendly call to anyone feeling a bit 'locked up' during the Covid-19 crisis.

Meanwhile, the new Carers' Focus Group is helping us to understand more of the challenges you face in supporting someone with PF, and support has grown further with the new PF-Tx support group for transplant patients and those awaiting a transplant. You can read more about all these initiatives in this edition. So, there's plenty going on: we may be physically distanced at the minute, but we are still finding new ways to keep socially close.

Keep safe.

*Debra Chand,
National Support Manager*

Joanna Ruck and
Gillian Trippner



Personal stories

Still standing – after four months of shielding!

Action for Pulmonary Fibrosis Chair Steve Jones lived with IPF for eight years before having a single lung transplant four years ago.

It is now nearly four months since my wife and I started shielding. On balance, it's not been too bad. We are lucky to have a garden and live in a village where we can go out for walks, while easily keeping two metres away from others. The early anxieties about whether pulmonary fibrosis patients were 'on the list' or not and the confusion about letters seem a long time ago.



In some ways, we have enjoyed shielding. Spending more time at home and travelling less on APF business has been good. I am also proud of the way APF quickly scaled up our support line to help those who have been finding shielding difficult and persuaded the government to recognise ILD patients as 'clinically extremely vulnerable'.

The main downside for us has been not seeing our grandchildren, though we can now meet them in the garden. Also, I don't know about you but, after months of lock-down, I miss doing the simple things like seeing friends, buying our own groceries and watching life go by while sitting in a café!

From 1st August, the government advice is to adopt 'strict social distancing rather than shielding'. We will be able to go outside to buy food, visit places of worship and return to work so long as we can observe strict social distancing.

After shielding for so long, it will be difficult to decide how much to relax. The government will issue further advice but APF will also be there to help you assess the risks associated with different activities and to decide what you, as an individual, feel safe doing. And, to end on a positive note, we've got this far and I believe have all shown that we are more resilient than we think! ●

Support

PF Awareness Month – The time to talk about lung fibrosis is NOW

Action for Pulmonary Fibrosis is joining people across the world during PF Awareness Month in September to spread the word about the disease.

We know that many of you like to contribute and feel part of the worldwide PF community during this special month. And there is no-one better than you – the patients and families who know exactly what it means to live with this disease – to raise awareness.

APF is gearing up to **Pulmonary Fibrosis Awareness Month**, and IPF World Week which falls in the middle of the month on **12-19 September**.

As we face the new normal, with Coronavirus still very much in the community, we are still hearing the feelings of isolation and 'forgotten about' that you have been experiencing. We know that there has never been a tougher time to live with a lung condition. People with pulmonary fibrosis perhaps understand better than most what Covid-19 might feel like.

To support you during PF Month we will be hosting a research webinar and holding a series of podcasts around mental health.

If you are able to fundraise for us in September, so that we can reach more people affected by the disease, we have some great ideas to help you. Take a look at our Create a Stir fundraising ideas on **Page 4** for inspiration.

'But we are also planning a national awareness-raising campaign because there is no better time to shout about lung fibrosis than NOW.'

We want you to join us in campaigning for pulmonary fibrosis to be kept at the forefront of any decision-making when it comes to Coronavirus.

We are busy planning right now but we will be sharing our campaigning plans with you very soon – keep an eye on our website, Facebook and Twitter for details. We hope you can join us **Pulmonary Fibrosis Awareness Month** this September. ●



The US PF Foundation is helping to raise awareness around the world.

Get involved

New group for transplant patients

The challenges of lockdown have spurred APF Chair Steve Jones to set up a new virtual support group for anyone with PF who has had, or is on the waiting list for, a transplant.

The new PF-Tx Support Group is an opportunity to share experiences and mutual support, and engage with experts. Dr Jas Parmar, Consultant Physician with Papworth Lung Transplant Service talked to a recent meeting of the group.

Steve had a lung transplant a few years ago and understands the many challenges facing those waiting for or recovering from a transplant, from the demanding preparations for surgery to ensuring a good recovery.

The group would be delighted to welcome new members! For further information contact steve@actionpf.org or on **07887 854940**.

Create a Stir! in PF Awareness Month

This September, during Global Pulmonary Fibrosis Awareness Month, we are asking all our wonderful APF supporters to get involved and Create a Stir! for people affected by PF. Invite your friends and family to join you to help us raise awareness and funds, and you will make a big difference to the 70,000 people affected by PF in the UK each year.

Getting involved is easy – we are asking you to hold a party and we will give you all the support you need. There are three types of parties you can host. Just decide what type of stir you want to create and ask your friends to make a donation to join your party!

Let's Brew This!

Simple and traditional, everyone loves a brew to catch up, have a natter, eat treats and raise some dough.

Shaken or Stirred?

A cocktail party is a great opportunity to gather together good friends and enjoy a delicious cocktail. You can swap recipes and get creative with some home-made decorations.

Milk it!

A milkshake party is a great way for children to fundraise and get their friends involved. It could be a double chocolate milkshake or even a fruit and yogurt shake. Inspire your little ones to try out their own recipes and get imaginative!

We'll provide you with everything you need to make your party a success. Banners, balloons, invitations, recipe cards and much more. Sign up today on our website www.actionpf.org to Create a Stir for those living with pulmonary fibrosis.

Every penny raised will help us in our fight to:

- raise awareness of pulmonary fibrosis and its impact on patients and families
- increase support for those affected by pulmonary fibrosis
- grow research into the disease and treatments, which could one day lead to a cure.

If you are shielding, you can still host your own Create a Stir at home event by grabbing your phone, iPad or laptop, and having your party via video link. Just invite your loved ones to join you and make a donation. We can help you to navigate Zoom, WhatsApp group-calls and other free online ways of connecting with your friends and family.

If you'd prefer to do it in person, we can help you make sure you follow the government guidelines of social distancing to keep you and your party guests safe. Mae and Louise Saunders (pictured) will be hosting a milkshake party this September and raising money for APF. ●



Mae said:

'We are really excited to host our own milkshake party and invite some of our friends to try out our own recipes. We will be asking everyone to donate £3 each for a milkshake and a homemade cookie. We hope to raise lots of money that will help people with pulmonary fibrosis.'

Fundraising stars

The fundraising team have been blown away by the dedication our fundraisers have shown during these unprecedented times. They continue to adapt their challenges during lockdown, raising much needed funds for Action for Pulmonary Fibrosis. Here are just a few of their stories.



Lesley Cully lost her mum to PF in 2017 and last year raised over £3,000 running the London Marathon in her memory. Lesley then joined the 2020 London Landmarks half marathon but, when the run was postponed, she went ahead with her own Local

Landmarks challenge. 'I'm delighted to support APF. It's a fabulous charity and every penny goes to such a great cause.' Lesley has also been busy making face masks using left over fabric. So far she's made masks for over 40 people, raised over £400 and has sent them all over the country and to America!

'This new virus is showing how terrible it can be to not be able to breathe and so to protect in a small way against that by wearing a mask and raising money at the same time was a perfect fit,' she said.



Friends and colleagues of **Mick Johnson**, who starred in the BBC1 series Ambulance, are collectively walking 75 miles in his memory. Sadly, Mick died in March, having been diagnosed with PF in

2018. Close friends at Tollgate Ambulance Station in Stafford worked within distancing guidelines to hold their fundraising event on what would have been Mick's 75th Birthday in June.



Dennis Barber was Chair of the support group for Wythenshawe hospital, helped trainee doctors and nurses there and took part in several clinical trials while living with PF. Sadly,

Dennis passed away due to Covid-19 this year. His family were unable to have a proper send off for him, so daughter Kirsty set up a Just Giving page in his memory which has already topped £1,000: 'He would love to see APF get all the help they need to do research on his illness.'



Lily, aged only nine, wanted to raise funds for APF in memory of grandpa Keith Barnard. She designed a poster to promote her event – cycling 150 times up and down her driveway at home – and managed to raise £175. Thanks Lily for cleverly adapting your fundraising event during lockdown and staying safe!

Don't forget, if you are planning a personal challenge to raise funds for APF, email the team and let us know what you are planning at fundraising@actionpf.org ●

Celebrate with us

During September's Awareness Month, we are asking for our supporters to do something amazing and donate their celebration to Pulmonary Fibrosis Month. Whether it's a birthday, anniversary or retirement, you can ask friends and family to make a donation to APF in lieu of a present.

Facebook Fundraisers are quick and easy to set up. Facebook will prompt you to set up one for your birthday or you can do this yourself. You'll also be able to add a donate button to your page, posts and video, making it easy for your family and friends to contribute in a few taps.

Whatever time of year you're celebrating your special occasion Facebook Fundraisers are an easy way to raise money for APF.

Fundraising

APF – here for you now and in the future

- ‘Living with pulmonary fibrosis can be isolating as your independence declines. Living in lockdown and self-shielding makes this worse. The risk of contracting covid-19 is frightening for both me and my family.’

2020 has been a year like no other. During these challenging times Action for Pulmonary Fibrosis has responded quickly, adapting our services so we can continue to support patients and families when they need us the most. We have:

 - Successfully campaigned for PF patients to be included on the shielding list to ensure they can access support services and priority shopping
 - Trained a new team of dedicated telephone support volunteers, providing a listening ear to anyone feeling isolated or anxious during this time, in addition to our Support line
 - Reached over 5,500 people through our online coronavirus hub and newsletters providing relevant, up-to-date information to help patients and families keep safe and well. Take a look at actionpf.org/information-and-support/coronavirus
- Helped support groups to meet virtually so anyone affected by PF can stay connected to their groups
 - Successfully campaigned for IPF patients to be given priority for the lung function tests they need to before prescribing antifibrotic medicines
 - Continued our research programme to create a better future for anyone affected by PF.

APF has increased support for people affected by PF during this time, but we have unfortunately seen a drop in funds due to the Covid-19 pandemic. This fall in income comes at a time when our work is needed most. Please support our Coronavirus Appeal raising vital funds towards our essential services at justgiving.com/campaign/apfcoronavirus so that we can continue to be there for patients and families affected by this devastating disease.

Your donation will help us continue to respond and adapt our work as government advice changes, so we can ensure our community does not feel forgotten, and that nobody need face PF alone either now or in the future. ●

Visit: justgiving.com/campaign/apfcoronavirus or complete this form

Please return to: **Freepost Action for Pulmonary Fibrosis** (no other address details needed)

Name	
Address	
Postcode	
Email	Phone

I would like to donate **£10** ☐ **£20** ☐ Other amount

- ☐ I'd like to donate by **BACS** to:
Account Name: Action for Pulmonary Fibrosis
Sort-Code 40-52-40 Account No. 00023412.
- ☐ I'd like to donate by **cheque**.
Please make payable to Action for Pulmonary Fibrosis and enclose with this form.

Boost your donation by 25p of Gift Aid for every £1 you donate. Gift Aid is reclaimed by APF from the tax you pay for the current tax year. Your address above will be used to identify you as a taxpayer.

☐ I want to Gift Aid all my donations to Action for Pulmonary Fibrosis. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gain Tax in the current tax year than the amount of Gift Aid claimed on all my donations it is my responsibility to pay any difference.

Please notify APF if you want to cancel this Gift Aid declaration, change your name or home address or no longer pay sufficient tax on your income and/or capital gains. If you pay income tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self-Assessment tax return or ask HM Revenue and Customs to adjust your tax code.

Support us with a donation

Personal stories

Stories from the NHS frontline

Action for Pulmonary Fibrosis Chair Steve Jones shares his thoughts on the NHS frontline workers, and we hear first-hand from two clinical colleagues.

It was wonderful to see everyone showing their appreciation of the NHS, week after week, during lock-down. We clapped for the front-line workers on Covid-19 wards, but we were also saying thank you to the NHS as a whole.

When I joined APF, I realised that this sense of community exists across the country. NHS staff are involved in most of the 80 patient support groups. The charity receives great support from leading doctors and nurses. They are always willing to go the extra mile for patients.

This was clear when Coronavirus hit, as health professionals across the country had to face a new challenge. Three cheers for the NHS!

‘Covid-19 brought changes for all of us,’ says **Sandra Olive**, Nurse Consultant at Norfolk and Norwich University Hospital. ‘Wards and clinical teams reorganised, guidance for practice was re-written and skills refreshed in preparation for our altered roles. I spent the first few weeks providing training in respiratory nursing and hands on support for the inpatient nursing teams – an education for me too, having not worked for long periods on wards for many years.

‘The uncertainty and speed of change was challenging but there was a real sense of working together and supporting each other.

‘The period following the ‘peak’ has, in some ways, been as difficult as we try to organise services differently. Crowded waiting rooms are a thing of the past, our capacity to do breathing tests is limited and most of our consultations are taking place via video or telephone calls. Urgent appointments have continued but facemasks and safe distancing make this a very different experience.’



Mark Major, Specialist Nurse with Hull University Teaching Hospitals also reflects on the challenge: ‘We were planning for, and expecting the worst. Clinics closed, wards emptied, new makeshift ICUs opened and staff redeployed into the unknown.

‘I returned from holiday early to help steady our pulmonary fibrosis ship. All clinics were converted from face-to-face appointments to telephone consultations and home visits were for urgent care only. We manned our phones and reassured patients as the calls came in. I provided teaching on Covid-19 wards to staff unfamiliar with high flow oxygen in readiness for the influx of patients.

‘Fortunately the wave never came – more of a ripple! Demand for beds was steady but low. We found our new way of reviewing patients strange but more efficient and some of our patients preferred it. ●



‘We are now planning our recovery phase and reopening clinics, albeit in a new look system without relatives and loved ones. We remain in uncharted waters but we are seeing light at the end of a very dark tunnel.’

Making Carers Visible

At Action for Pulmonary Fibrosis we know that a diagnosis of pulmonary fibrosis has a huge impact on everyone in the family. While the patient is always at the centre of our work, we also want to support carers and families. During Carers' Week in June we held an online Carers' Forum to gather the experiences and views of those of you in the 'front line'. It was a privilege and a revelation to hear from those who took part.

Here are some of the highlights:

- Although most people agreed that the term 'carer' isn't perfect nobody objected to being called a carer. 'Whilst you are a husband, wife or partner personally, for people looking in you are a carer.' The American term 'care-giver' got a resounding thumbs down!
- Information and signposting to charities like APF at the point of diagnosis was badly lacking.
- Knowledge of doctors and nurses not involved in respiratory care was generally poor. 'I have been in a hospital emergency department when a doctor 'Googled' pulmonary fibrosis,' said one carer.
- Agreement that palliative care – although a term that many patients are frightened of – should be introduced earlier as a way of living better.
- A suggestion for a 'buddy' system between carers.

I am sure these comments will resonate with many of you reading this. If you would like to get involved in our Carers' Forums please contact us (details on the back cover). Your input will inspire our developing support services for carers. Watch this space!

Supporting carers in West Kent

We asked Dee Bryan to tell us about the carers group she set up last year. Dee cares for husband, Roger, who was diagnosed with IPF in July, 2016 and the couple also set up the West Kent PF Support Group. 'With my background as a Complementary Therapist in cancer and palliative care and my needs as a carer myself, I felt it was a natural progression to start a carers' group last year. It provides an open, confidential, safe space for carers to express their worries, concerns and fears along with being able to laugh and cry without upsetting loved ones. With the lack of psychological support for patients and carers from the point of diagnosis, support groups have been invaluable. As a carer myself, I knew that others must share my worries and fears. There isn't any particular format, we just talk about things very naturally and encourage people to express their emotions.'

'As a carer myself, I knew that others must share my worries and fears.'



From left: Jenny, Anne, Dee and Jean from the West Kent Carers Group.

HM The Queen spoke to carers via Zoom during Carers' Week.

And who better to tell us how this group helps than three of the members themselves?

'The group has been a great support to me. Before my husband's death there was good advice from the others which helped me get information and support. Since then it has meant the world to me to speak to people who know they will face a similar end and be alone. They are there for me anytime I need them.'

'I feel like our little group are all on a journey through pulmonary fibrosis together and when the road gets rough for one of us, the others are there to help, support and comfort. It helps me to know that as heart-breaking as it is when you reach the end of the road, with family and friends around you, you will get through it.'

If you would like to talk to Dee about setting up a Carers' Group please contact her at deebryan@me.com or call on **07775 616769**.

And you'll find support and advice on our website actionpf.org/information-and-support/carers-family-friends ●

Wendy Dickinson, APF Trustee

'Just knowing the others were going through similar problems has really helped as it's reassuring to know I am not alone. Also, to have a little rant or let off steam in the company of others that aren't going to judge you, but listen with empathy, especially as the disease progresses.'

Support

APF Coronavirus Hub – all you need to know in one place



The Covid-19 pandemic has been with us for six months and the information coming from all sides can, at times, seem overwhelming. To support all those living with pulmonary fibrosis we have set up a Coronavirus Hub on our website to bring together, in one place, all you need to know to stay safe.

Check it out here actionpf.org/information-and-support/coronavirus

FAQs All your questions answered, from advice on wearing facemasks to changes to guidelines on shielding

Support and connection Details on how to stay connected with friends and family via WhatsApp, Zoom or Skype

Your wellbeing Support and advice on maintaining good mental health during the crisis

Videos Lots of great advice on exercise, diet, zooming and much more.

The Hub is constantly updated as advice and guidance changes. If you think we've missed something or have unanswered questions please let us know by emailing us at info@actionpf.org or call our Support line on **01233 785 725**.

Health tips

Techniques to help with breathlessness

Breathlessness can be a frightening and distressing symptom of pulmonary fibrosis. You can learn how to minimise, cope with and manage this symptom – and make a big difference to your quality of life.



Breathing control

This is useful when you're short of breath or feeling anxious. Your diaphragm contracts when you breathe, pulling the lungs down, stretching and expanding them. It relaxes back when you breathe out, reducing the amount of air in your lungs. To control this takes practice and the best time to practice is when you are relaxed and not out of breath.

- Get into a comfortable position, with your arms supported and your shoulders relaxed. Put one hand on your chest and the other on your abdomen. Close your eyes to help you relax and focus on your breathing.
- Slowly breathe in through your nose, with your mouth closed. If you're relaxed, the air will reach low in your lungs. Your abdomen will move out against your hand.
- The hand on your chest should hardly move. Breathe out through your mouth. Your abdomen will fall gently. Imagine the tension in your body leaving as you let the air out. Use as little effort as possible and make your breaths are slow, relaxed and smooth.

Feeling out of control

For those times when you are too breathless or anxious to manage breathing control, simply:

- Gently fan yourself
- Lean forward
- Focus on longer out-breaths.

Pursed-lips breathing

Breathe in through your nose, then purse your lips as though you're going to blow out a candle. Blow out only for as long as is comfortable – don't force your lungs to empty any more than feels natural.

Blow-as-you-go

Blow-as-you-go helps make tasks and activities easier – especially those that make you breathless. You can use it with pursed-lips breathing. For example, when standing up, breathe in before you stand up, and then blow out as you stand up. Try using pursed lips as you blow out.

Paced breathing

Paced breathing is useful when you are walking or climbing stairs. You pace your steps to your breathing. You can use it at the same time as pursed-lips breathing and blow-as-you-go. Breathe in for one step and then take either one or two steps as you breathe out. Take more steps as you breathe in or as you breathe out, if that feels better for you. Try different combinations to find what works best.

Start singing!

Some patients have found singing to be beneficial, although it doesn't suit everyone. A number of support groups have invited singing coaches to their sessions and found this very useful. ●

You can find more about breathlessness on our website:

actionpf.org/information-support/breathing-techniques

Hull York medical school also has a useful guide to living well with breathlessness:

hyms.ac.uk/assets/docs/research/bringing-breathlessness-into-view.pdf

and carers may want to look at this supporting breathlessness resource:

supporting-breathlessness.org.uk

Support

Volunteer telephone ambassadors waiting for your calls

A new APF telephone service is now 'live' to support people living with pulmonary fibrosis during the Covid-19 crisis. Action for Pulmonary Fibrosis has trained telephone support ambassadors to add to our existing ILD nurse-led Support Line service. Our volunteers are either PF patients, carers or former carers and they understand just how tough life with pulmonary fibrosis can be.

You can refer yourself or we can receive referrals from health professionals and support groups (with your permission), for anyone over 18. Anyone who would appreciate a call should let us know at support@apf.org or on 01223 785725.

We'd be happy to answer any questions you have, check that you are getting the support you need and to signpost you to other services, including PF support groups and our own nurse-led Support Line.

The volunteers are given training (including on wellbeing and safeguarding) and have a support supervisor. They also have a What'sApp group. Volunteer Administrator Emma keeps everything on track with details of who to call.

Nurse consultant Dr Karen Marshall said, 'I have been very interested in the psychological impact of respiratory conditions and I was delighted to be asked to work with APF to help train volunteers, developing their current skills to discuss emotional wellbeing with people they may be in contact with. It is important to address physical and psychological needs and I was

'I welcome the work that APF is doing to provide telephone support volunteers for peer support and will be ensuring that our patients are aware of this valuable help.'

Sarah Lines, Respiratory Nurse Specialist

Gordon enjoys a pint, pre-lockdown!



Patient reaction:

'We talked about dogs, the weather, disabled horse riding, Cumbria... just lovely...'

so impressed by the enthusiasm of the volunteers. I know they will make such a huge difference to many people.'

APF will be running more training soon and we'd love to hear from anyone who is interested in becoming a telephone support volunteer!

Gordon Harrison, Vice Chair of Sheffield PF Support Group said, 'As support group leaders, our first priority was to get members recognised by the Government as being extremely vulnerable, which we did with the assistance of APF.'

'What is proving to be challenging now is how best to support those who are trying to cope emotionally with the twin pressures of a serious health condition and long-term self-isolation. That's why we are so pleased to hear about the telephone support service for those who, in many cases, just need a sympathetic but informed ear.'

Sarah Lines, Exeter Support Group lead and Respiratory Nurse Specialist, commented, 'With limited work time our conversations often focus on clinical needs. I welcome the work that APF is doing to provide telephone support volunteers for peer support and will be ensuring that our patients are aware of this valuable help.' ●



Karen (second right) at the British Journal of Nursing Awards last year



Sarah Lines (next to display stand on left) with colleagues pre-Coronavirus.

Support Group Round-Up

Zooming through the Coronavirus crisis

You've probably noticed that our regular round-up of support group activities looks slightly different this issue! We love to feature your events, talks and meetings but the Covid-19 pandemic has put paid to most things 'normal'. However, you haven't let it stop you connecting with us and with your support group friends. We've been really impressed by the efforts of many groups to keep in touch. We can't mention every group here (you know who you are!) but here is a shout out to a few, and news of what APF has been doing to stay connected.

When lockdown was announced on March 23, few of us imagined how long and how difficult it would be. Even now the PF community still has the prospect of months more of restrictions to our normal lives until a vaccine or effective treatments are found. As well as the worry of having pulmonary fibrosis and the chance of being exposed to Coronavirus, we have also been coming to terms with not seeing friends, children and grandchildren for many months.

BUT – in the face of adversity we suddenly discovered an amazing new resource to help us cope: Zoom and online wizardry. What a blessing Zoom and other technology has been, not only enabling us to see and speak to our loved ones but interact as a group as well.

Obviously, nothing can replace face-to-face contact with other people but positives and possibilities have emerged from our experience of Zooming. For a start, many of us who remember pre-internet days, have learned new skills and new ways to connect which could really enrich our lives in the future.

Zoom has also been a brilliant way for APF to stay in touch with the network of 70+ support groups across the UK and for support groups to stay in touch with their members.

APF's first Zoom meeting

Our support team, led by Debra Chand, organised APF's first Zoom meeting just a few days after lockdown and over 30 group leaders took part to contribute to our support plans during the crisis and to tell us about how they were coping.

Support Group Round-Up (cont.)

It is a great mutual support network and we now hold Zoom meetings for group leaders every three weeks, alternating between national and regional meetings. It supports the leaders during a very difficult time and a bonus has been that our two new regional co-ordinators, Jo Ruck (Northern Region) and Gillian Trippner (Southern Region) are able to put faces to names as they both started their jobs after lockdown. They are looking forward to meeting you face-to-face eventually.

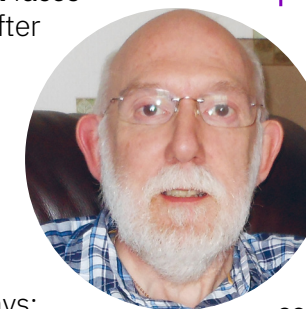
Support Group zoomers

Bolton PF Support Group has been leading the way with online meetings even before lockdown was imposed. Group leader, Steve Milward (pictured), says: 'We realised that this was approaching and we arranged our first virtual meeting a couple of weeks before March 23.'

Steve did his research and decided against Zoom, instead choosing the free service, Google Meet as the platform for Bolton's meetings. He has also organised weekly live pulmonary rehab exercise classes for members with the help of Tom Allerton, Specialist Respiratory Physiotherapist Principle Service Lead at The Royal Bolton Hospital. Steve says:

'I've been on two eight-week PR courses and they were great. You are supposed to carry on the exercises at home afterwards but, despite all good intentions, not many people do. Bolton Age UK has kindly given us the services of physio Niall Bradley, Strength and Balance Team Leader, for our weekly online sessions. Everyone who takes part really enjoys it and feels the

benefit. It's not only good for health but is also a social and fun activity. Laughter helps to expand the lungs!'



Steve is even now planning for the future: 'There are people who want to come to our face-to-face meetings – in normal times – but just aren't up to it and some regulars who are just too poorly on the day. I already have a state-of-the-art webcam and we've received a local community grant to buy some new software

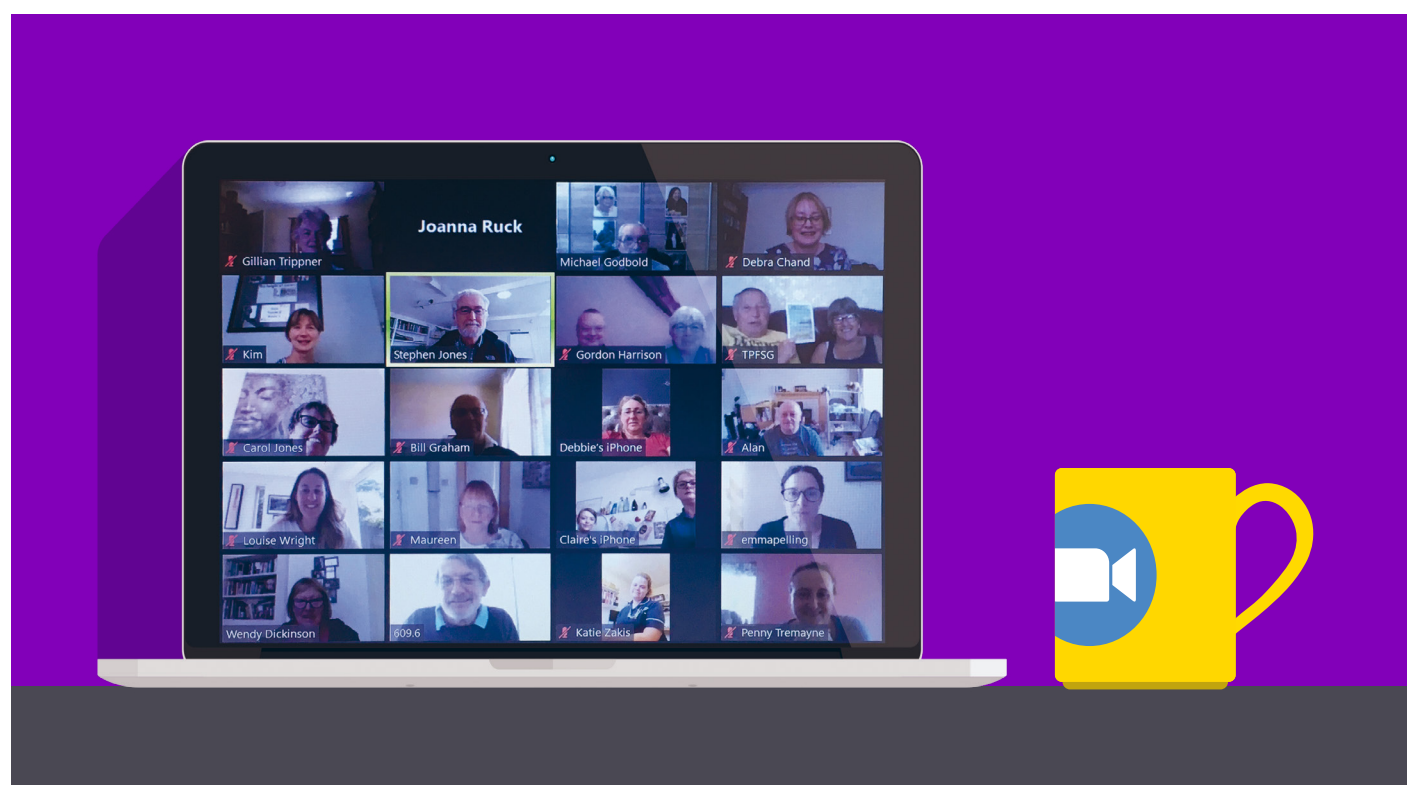
and a video camera controller which will help us broadcast our meetings live into members' homes. We definitely want to continue with virtual meetings post-Covid.'

Other groups that are embracing technology to support their members include St Georges (London), Tameside, Papworth, West Kent, Kettering, Derby, Nottingham, Leicestershire, Leeds, Sheffield, Manchester, Bolton, Reigate, Chorley and Preston, Imperial (London), Sutton Coldfield, West Bromwich and Berkhamsted. Please let our support team know if you have been Zooming. ●

Wendy Dickinson, APF Trustee

And don't forget WhatsApp

If you don't fancy appearing on-screen or just can't master the technology, WhatsApp on your phone or tablet is a great alternative. APF Trustee Howard Almond manages a WhatsApp group for the Plymouth and Exeter Support Groups with the help of ILD Nurse Specialist, Sarah Lines. There are around 20 members and many have never attended a face-to-face meeting as they are too far away or are newly-diagnosed. Howard says: 'Early conversation was about getting supermarket deliveries and who to contact for support but now I post Covid-19 and research news and the work being done to get clinics up and running again. It works well and people can ask questions and raise issues whenever they like.'



Your feedback is invaluable – Thank you!

**APF
Covid-19
Survey**

‘APF is run by people who have or know someone with PF. They know and fully understand the condition, how it affects the person, their lives and their families, friends and carers. They have everyone’s interest at heart and always go the extra mile to help, which means everything.’

A huge thank you to everyone who completed our Covid-19 Survey. We had an overwhelming response and have gathered feedback from over 500 people. You gave us some essential insights about how the crisis was affecting you. We also received some lovely comments which inspire us to continue to drive positive change for anyone affected by pulmonary fibrosis.



Isolated and forgotten

A quarter of you (25%) said you did not receive a letter advising you to shield at the start of lockdown and a third (31%) said this made you feel isolated and forgotten. Almost three quarters (73%) said the biggest concern at this time was not being able to access priority slots for supermarket shopping.

Pulmonary fibrosis patients were initially not included on the list of extremely vulnerable people, which would give them access to priority support and services. APF campaigned to change this and PF was eventually included.

‘Just to thank APF for getting PF patients recognised as extremely vulnerable during the crisis. They had been forgotten which was really worrying and upsetting. Positivity is the key – knowledge and inspiration underpins this!’

Unsurprisingly the Covid-19 pandemic has made the vast majority of you more concerned about your lung condition and over half (54%) are concerned about not having regular tests at hospital.

APF has successfully campaigned directly with Health Secretary Matt Hancock on this to ensure that PF patients are given priority for lung function tests. We will be monitoring the situation to make sure the new system is working.

75% of you said the communication and information supplied by APF during the pandemic has been relevant. This is re-assuring for us and we will continue to ensure our Coronavirus Hub is kept up to date.

As always, research and increased awareness of PF remain a high priority for our charity. As Pulmonary Fibrosis Awareness Month in September approaches we’ll be using the statistics, insight and anonymous quotes from you to drive awareness, understanding and fundraising for our work. The full report will also be available on our website. ●

Research focuses on Covid-19 impact



Professor Gisli Jenkins

In this issue’s research round up, Action for Pulmonary Fibrosis Chair Steve Jones looks at key Covid-19 stories.

Can Covid-19 infection cause pulmonary fibrosis?

Doctors in the UK are concerned that serious Covid-19 infection might cause pulmonary fibrosis in some patients.

It is unlikely that those with a mild form of the disease will suffer permanent lung damage. But those in hospital, especially those ventilated in intensive care or with a serious infection, may be at risk.

Over 100,000 people in the UK have needed hospital care for Covid-19 since the pandemic started. Tens of thousands of these people will need to be recalled to hospital to check if they have been left with permanent damage.

Dr Sam Hare of the Royal Free Hospital Trust in London says that early signs of damage are being seen on some follow-up CT scans: ‘At six weeks you would expect the scan to have returned to normal but 20% to 30% of patients, who have been in hospital, appear to show some early signs of lung scarring.’

Other doctors note that many post-Covid patients have persistent breathlessness.

APF Trustee, Professor Gisli Jenkins from Nottingham NHS Trust, said: ‘My main concern is that never before in our lifetime have so many people been subject to the same injury at the same time. It will be many months before we can be sure if post-Covid patients have lung fibrosis and whether this gets worse over time.’

Urgent research is needed to determine how many people recovering from Covid-19 infection have developed fibrosis and to identify those with progressive lung fibrosis who will need long-term care. Gisli went on:

‘Covid-19 is the nastiest viral pneumonia I have ever seen. We are nowhere near herd immunity yet so everyone, especially patients already living with chronic lung disease, should be very careful to avoid infection and observe social distancing.’

Charities like Action for Pulmonary Fibrosis will be needed more than ever in years to come.

Vaccine development

Most of us living with PF will need to remain vigilant about social distancing until there is a vaccine.

Vaccines generally take over 10 years to develop but everyone is hoping that this time it will be different. Eleven vaccines are already in clinical trials around the world. In the UK, researchers at Oxford University and the pharmaceutical company AstraZeneca hope, if their on-going trial is successful, to have their vaccine (AZD1222) approved this year. Scientists at Imperial College London are not far behind.

While there are early indications the Oxford vaccine works, there is more to do to assess its safety and efficacy. Some optimists believe that millions of doses will be ready for roll-out by the end of 2020, but most commentators think 2021 is more likely. ●

Staying in touch with Action for Pulmonary Fibrosis

We would like to keep in touch with the information you want to receive, in the way you prefer. Please tick the boxes to let us know what updates you would like to receive and how:

- ☐ APF Newsletter including news on the latest research, support for you or a loved one and fundraising
- ☐ Updates on fundraising events you can get involved with
- ☐ Campaigning information and how you can get involved
- ☐ Information on ways to donate to APF

Would you prefer to be contacted by:

- ☐ Email ☐ Post ☐ Phone

Name	
Address	
Postcode	
Email	Phone

Please return to: **Freepost Action for Pulmonary Fibrosis** (no other address details needed)

You can opt out at any time by emailing optout@actionpf.org with your name and address, or phone **01733 475642**



Support

APF Telephone Support Line

It's no surprise that the APF Support Line has experienced an increase in calls over the past three months. ILD Nurse Lucy is there to give tailored advice on pulmonary fibrosis. Recent enquiries have been about shielding and concerns over delayed appointments but lots of general questions about living with PF as well.

It is important for APF to keep in contact with our patients so that we understand your concerns and accurately represent and support you, so we encourage patients and carers to keep calling.

As one caller said, 'If it's not Covid the NHS doesn't want to know. I feel abandoned. Thank you for listening and helping me form a plan.'

Find more information here:

actionpf.org/information-and-support/support-line



**Action for
Pulmonary Fibrosis**

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