

APF Insider

Support — Research — Educate — Campaign



A support group meet-up in an ASDA car park and a bereaved son raising awareness in Northern Ireland in a very unusual way!

See page 5 for the full story.

**Getting back
to normal?
See page 8**



PF Month is on its way

We're gearing up for our biggest opportunity to raise awareness and funds for pulmonary fibrosis. This year, we're putting the spotlight on the impact of a persistent and uncontrollable cough.
See page 6 for details on how to get involved.

NICE success story

We're delighted to announce that our campaign – backed by patients, families and medical experts – to end the restrictions on anti-fibrotic drugs has successfully reached its next step. NICE has agreed to review its decision that currently restricts access to anti-fibrotic treatments. **See page 7 for the full story.**

Who we are and what we do

A message from our CEO

For us at APF, July marks the start of a new financial year, helping us to reflect on the past 12 months and look to the year ahead.



Covid-19 has brought enormous challenges, but opportunities too. We now exist in a world that is more aware of lung health and its impact on our daily lives. Pulmonary fibrosis and Covid-19 have proved to be a deadly combination and the necessary expansion of our services has brought us great pride, especially with the launch of our telephone befrienders and more recently our research champions.

Our services are needed more than ever, but we face our toughest year yet as emergency income for charities comes to an end. Together with our growing network of people living with PF, our families and professionals, we must use the sense of urgency we all feel to look beyond the daily challenges and seek every opportunity to tackle the increasing inequalities facing people living with PF now and in the future.

We thank you for your continued support; it means more than you probably realise.

Louise Wright

APF recognised as a charity in Scotland

Although APF services have always been available in Scotland, we wanted to demonstrate our commitment to full recognition as a charity in Scotland to enable us to extend our work. We're therefore delighted to announce that we have now registered with the Office of Charity Registration Scotland (OSCR).

We currently provide our full range of support for individuals and support groups in Scotland and intend to develop our presence further with the appointment of a Support Co-ordinator. We have been involved in the establishment of support groups in Aberdeen and in Fife and Tayside over the last five years and a new group has just been established in Forth Valley.

APF is already a contributor to Scottish Medicines Consortium consultations on drug therapies and



Here to help

Visit our website and Coronavirus Hub:
www.actionpf.org

Speak to our Support Team:
support@actionpf.org

Call our Support Line: 01223 785725

Call our Support Line Volunteer
Befrienders: 01223 785725

www.actionpf.org



treatments and the Scottish Parliament cross party group on Lung Health. Being registered with OSCR will strengthen our position in representing patients.

APF Trustee Elizabeth Bray commented,

"This is a great boost for our work in Scotland. We are also very grateful to our many fundraisers there and keen to provide further support for them as well as encouraging more people to get involved with events such as the kilt walk."

Welcome from our Chair

On July 19th, the government lifted all Covid-19 restrictions so things should be getting back to 'normal'. But what does this mean for pulmonary fibrosis patients? At APF we know the lifting of restrictions brings uncertainty and confusion for many with pulmonary fibrosis. Once again, people with PF are not feeling prioritised despite being the most vulnerable group. We want to see the UK government put CEV people first and foremost and we'll continue working alongside others in the sector to keep the pressure on.



As a community, we are quite good at avoiding respiratory infections like flu – especially in winter. But despite our two jabs, we still need to consider the risk of catching Covid-19. No vaccine is 100% effective, even for the healthiest people.

The ZOE Covid study being run by Kings College London shows this risk is very low for people who have had two jabs (about 1 in 2500) but is likely to be higher for older people and those with chronic lung disease.

Research by APF trustee Professor Gisli Jenkins shows that PF patients should be careful because, if they are hospitalised, they are more likely to get severe Covid and more likely to die. We also know the vaccines may not work as well in PF patients who take immune suppressants for their PF or, like me, who have had a lung transplant.

Over the last couple of months, I have started to get out more. Each week, I go for an e-bike ride with friends and have lunch in a pub garden. My wife Hilary and I have also been away to a country cottage with one of our children and grandchildren but only after negative lateral flow tests. As yet, though, I have only ventured inside a building a few times and only then if there are not many people inside. I am always well masked. Despite these restrictions, it is great to get out!

Looking forward, I will continue to wear a mask in closed public places, which as winter comes should also provide some protection against other respiratory infections too. I am also going to keep following the advice on 'hands, face, space, fresh air' to cut the chances of catching or spreading the virus.

As a transplant patient, I have to be especially cautious. But, if you do not take drugs to suppress your immune system, you can probably be confident that your two jabs will be providing substantial cover, and the booster jab we'll get in the autumn should help further.

The government says we should now take responsibility for our own decisions. So, how are you going to use your new freedoms? There is no right answer but talking to patients across the country I think most plan to be cautious and see how things develop. As a friend with IPF from Manchester put it:

"I am going to keep an eye on Covid rates in my area, ask advice from health care professionals, avoid coming in close contact with people I don't know – for example on crowded public transport – and wear a mask in public places".

Sounds good to me.

Steve Jones

Support Groups

Support Group Round-up



The Covid-19 pandemic has meant new challenges for PF support group members trying to remain in touch with each other during lockdown and extended shielding.

This hasn't been easy, but many groups embraced the challenge with determination and enthusiasm. Support group leads acquired IT knowledge and skills necessary to run online meetings – it has certainly been a learning process, and we should feel proud of what we have achieved.

The **Leicestershire Support Group** created a WhatsApp group and started monthly zoom meetings in May 2020. Sadly, they have lost several members of the group during this period. Telephone contact has been important to support their carers, as well as with those who have felt unable to use Zoom or WhatsApp. The group is now looking forward to resuming face-to-face meetings on 12 August.

Windsor Support Group restarted in March this year. Liz Robertson from the group told us,

"One of the great benefits of this Zoom era is that we can link up with people anywhere and make them feel welcome. And with help from Steve in the Bolton group and information from APF, Geoff Gardner created a website including a personal blog about his PF journey.

We have benefited in many ways from APF. Trustee Howard Almond in Exeter has shared information about research projects and attending the leadership meetings has given us access to information webinars, the EU-IPFF conference, and the research champions project."

Rising to the challenge

As confidence has grown several groups intend to continue online meetings in addition to face-to-face meetings in the future. However, online meetings aren't for everyone, and we can now start to look forward to the time when we can resume face-to-face meetings.

We have produced a 'crib sheet of things to consider' when meeting up face-to-face again – available from support@actionpf.org

*Jo Ruck,
Regional Support Co-ordinator*

Whilst waiting (and looking forward to) COVID being but a memory, the **Wessex Interstitial Lung Disease (W.I.L.D) Support Group** is relaunching with a virtual meeting on September 21. They're planning a talk from the experts (Dr Fletcher and Dr Spinks), break out rooms for patient and carers group catch-ups, an update on local ILD research opportunities, as well as sharing a virtual cuppa!



A new Support Group is forming in Forth Valley, Central Scotland. Thanks to the specialist respiratory nurses, who worked with APF Chair Steve Jones to bring it about. Chair Steve Chinn says,

"Support groups are invaluable for sharing experiences, and knowing you are not alone".

You can contact Steve at stevechinn@btinternet.com

Support Groups

Car park catch up!

Tom McMillan from Northern Ireland told us about a rather different approach to getting together and promoting his local group



"This was the day we had all been waiting for, 3 June 2021. The time was 4pm and the sun was shining brightly. It had been 15 long months since we had all met up, face-to-face – well, two metres apart and face mask to face mask.

I have never been one for getting excited when it comes to an ASDA visit. However, this day was very special. Members of the Northern Trust Support Group arrived one by one at Coleraine ASDA car park for a very special occasion. This was the first time that many of us had physically seen one another rather than Zoom: it does come as a bit of a surprise when you see the rest of the person below the shoulders!

The excitement was palpable. Not only had many of us not met anyone outside our bubbles for a very long time, but the press were also present, with cameras and note pads at the ready.

Then at just after 4pm, Martin Lynch arrived in his shiny truck and milk tanker to the applause of our support group members – horns blaring as if he had not already got everyone's attention. Martin's rig was emblazoned with the group logo and contact details, all at his own expense.

This was a day that will long live in the memory of many in our support group, including their families. The generosity of Martin Lynch touched all of us on the day. His father had died of IPF, but Martin and his family were not aware of our support group when his father was ill, hence his unique approach to raising awareness."

Welcome to Annabel

We're delighted to welcome Annabel Lotsu to the APF team as our Peer Support and Advisory Service Lead. Annabel, who will be overseeing the increase in support for patients and carers through volunteers, helpful resources and the Support Line, writes:



"I'm really excited to be joining the team and hope to meet many of you soon. I have spent many years in the charity sector, where I have been fortunate enough to work with and support the amazing contribution of volunteers.

I am a strong believer in the importance of peer support and I have seen first-hand the difference this can make in people's lives.

When I am not keeping busy with work, I do enjoy a good Netflix series and over the past year I've rediscovered the joys of running!"

Spring into Action has sprung!

Ten support group leaders took part in the pilot of Spring into Action training, covering aspects such as self-awareness, mindfulness, confidence, engagement and listening skills.

The aim is to build confidence, and the training is open to other groups and leaders – contact us at support@actionpf.org for more.

Lifting the lid on cough for PF month

It's that time of year again when we gear up for the biggest month in the calendar for patients, families and APF. As well as PF Month, the month of September includes IPF Week which runs from 18-25 September.

Uncontrollable coughing. Difficulty breathing. Disapproving stares.

A persistent and uncontrollable cough impacts almost every area of life. To compound this, PF is misunderstood. People assume it is infectious, and during the current pandemic there's a tendency to judge anyone who coughs in public.

As one person told us, "My cough can clear a supermarket aisle, but you can't catch PF." We want to change attitudes and help reduce the stigma that can come with cough.

Sixty-year-old Geoff Gardner from Sandhurst, Berkshire, who has IPF and suffers with a cough, says:

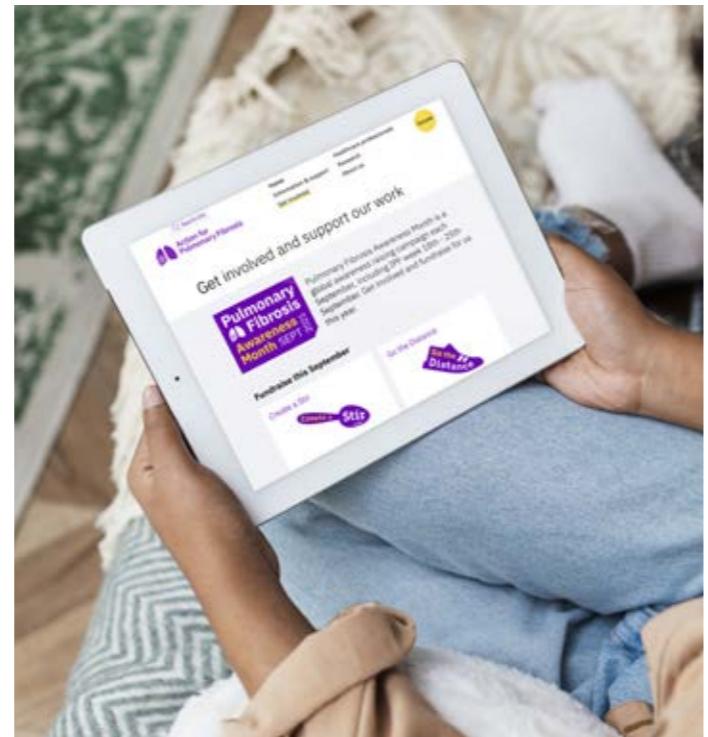
"A cough makes you feel like you're intruding on people. It can be as simple as biting into a piece of toast and a dry particle starts a bout of coughing. To be asked to leave the room – especially with Covid – is hard to handle. People jump to thinking the worst. When you're forever trying to clear your throat it can put pressure on a visit anywhere."



Geoff with wife Angela



Supporting you with your cough will be an important part of the month. We're developing ideas for a virtual patient event during PF Month where you can hear from both experts and patients about how to better manage your cough.



Can you help us spread the word during PF Month? We'd like to hear your views and support you to raise awareness in your area. Here are two ways you can get involved with our campaign around cough:

Can you help with our survey?

To support the campaign, we'll be running a short survey for patients, carers and loved ones. We'd love to get as many views as possible to understand the wider impact of cough. The survey has been shared online and is now live. Please look out for the survey link which will be shared widely.

Are you interested in engaging with your regional media for PF Month?

We'll be running an interactive and live media workshop on Thursday 12 August at 2pm. The session will cover how to write a press release or a letter to a news editor and tips on how to engage with the media during PF Month. Everyone is welcome and if you'd like to attend please contact emmab@actionpf.org

One step closer to anti-fibrotic drugs for all who need them

"NICE's decision to re-appraise the use of Pirfenidone and Nintedanib for IPF is the news our patient community has been waiting for. It will hopefully result in all patients having access to these treatments. I know from talking to patients and their families this news offers hope, but they are disappointed that the appraisal will take a year to complete. We need to ensure that access to these life-extending medicines happens as quickly as possible."

– Steve Jones

We're delighted that our four-year campaign, backed by you and the medical community, to end the inhumane restrictions on life-extending anti-fibrotic drugs has been successful.

In May 2021 NICE agreed to launch a re-appraisal of anti-fibrotic drugs for patients with idiopathic pulmonary fibrosis which will hopefully result in all IPF patients having access to the drugs. Patients currently only receive these treatments when their lung function dips below 80%.

NICE has agreed to do a full technical appraisal of both anti-fibrotic drugs to cover all IPF patients. The re-appraisal takes 50 weeks but we're keeping the pressure on to ensure there are no further delays. We will continue to encourage pharma companies and NICE to engage and make them aware that patients can't wait for another 12 months.

There will be no need for further campaigning until the preliminary verdict is given later in the year. We will report back to you as soon as we hear further news and feel optimistic that in 2022 these restrictions will be a thing of the past.



Steve Jones

We've also been campaigning for Nintedanib access for other forms of pulmonary fibrosis, such as Rheumatoid Arthritis, Asbestosis, ILD and other autoimmune diseases. We estimate two thirds of all pulmonary fibrosis cases are IPF and one third are other forms of progressive pulmonary fibrosis. Nintedanib was approved for other types of PF in Europe last July, it then goes to the member states to decide if they are prepared to pay under their health systems. NICE is doing this for England, and they are due to report in September.

Scotland started the process after NICE and they completed their review in May this year. Scotland has approved Nintedanib for other forms of PF which is great news. We're optimistic that in a year from now, restrictions will end and patients with all forms of pulmonary fibrosis will be given access to anti-fibrotics on the day of diagnosis (when appropriate).

This was a combined effort, a lot of work behind the scenes, and understanding what goes on inside NICE. The MP letter writing campaign was also a great help applying pressure. Congratulations to everyone involved.

NICE National Institute for Health and Care Excellence

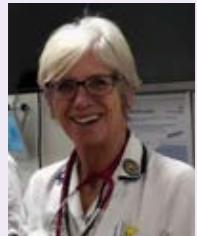
Health Tips

Getting back to normal

Excited? Terrified? A mixture of both? How are YOU feeling about getting back to the 'new normal' as lockdown eases? Our experts are on hand to answer some of your questions about getting back to mental and physical health.



Dee Bryan cares for her husband Roger who has had IPF for 5 years. Dee has worked in cancer and palliative care for 20 years supporting patients and carers. She's also practiced as a clinical hypnotherapist and psychotherapist for 12 years, helping people with anxiety related conditions.



Physiotherapist **Lorna Brown** has worked as a physiotherapist in respiratory care for many years and started the pulmonary rehabilitation service at Papworth Hospital in 1997. PR is something she feels passionate about.

Your questions:

Q1 I feel I've become a bit 'institutionalised' since shielding. I've got too used to being inside.

Dee: Many people will be feeling the same. We were told to stay at home and not mix with people and it doesn't take long for that to become ingrained in our minds. It's surprising how quickly we get used to change. Venture out gradually, it needs to be on your terms where you are in control.

Q2 Although lockdown has been eased I am still very nervous about being around people. Will I ever get my confidence back?

Dee: You will get back to normal, but it may take time. Don't put any pressure on yourself. Take small steps and start with meeting people on a one-to-one basis or in a small group. Do things you enjoy outdoors - it's easier and safer to be outside when the weather is good. Enjoy the little things that give you pleasure and your confidence will soon return.

Q3 I am fearful of going outside and worry that with Covid not going away this will be my life for ever.

Dee: It's true that we will be living alongside covid for some time. Again, just take it slowly. Do what's comfortable for you - there's no rush. But if things don't improve with time, you may need to seek professional help. When we are in a heightened state of anxiety, we perceive danger all around and feel we've lost control. It's important to know it's normal to feel like this after what we have been through.

Q4 I haven't done much exercise during shielding and now I don't have the strength or motivation to get moving again. I just can't be bothered.

Lorna: I can appreciate you may feel a bit overwhelmed....however something is better than nothing! Start small and build on that. For example, stand up from the chair five times several times a day. Use a table or work top to support you as you rock from your heels to your toes - a great work out for the lower leg muscles. Make sure you can raise your arms above your head and if your balance is good, try some wall push ups. When you feel a bit more confident you can start walking on the flat, increasing the distance each week.

The internet is full of exercise ideas but always start with low impact work. I would recommend the BLF exercise video.

Dee: Start off by going for a short walk with a family member or friend and build up very gradually. Maybe you can join your local Pulmonary Rehabilitation class again as many are getting back to face-to-face classes.

Health Tips



Q5 I used to love swimming. Is it safe to go to my local pool? Can Covid be passed on in the water?

Dee: It is perfectly safe to go swimming, and you can't get Covid from the pool, there are too many chemicals for Covid to survive. Check with your swimming pool when it's not too busy.

Lorna: Swimming is a great form of exercise as it has low impact on the joints, and you can also exercise in the water. However some people find the water exerts some pressure on their chest. My advice is, if you're keen, start cautiously and build from there.

Q6 I don't want to go to any big shops or touch anything. My hands always feel dirty and I feel I may be getting a phobia after all the hand sanitising.

Dee: Going to big shopping centres seems very daunting. Despite what other people are doing, continue to wear a mask when shopping. It will make you feel safer. It's understandable that people will have developed fears about hygiene after Covid. It may be worth speaking to your GP for some advice.

Q7 I used to be a regular blood donor. Is it ok to do that again?

The Blood Donor website has lots of advice about donating blood and coronavirus online at www.blood.co.uk or call on 0300 123 23 23.



IPF patient Marian Forrester (74) is chatty, sociable, positive and outgoing.

If you'd asked her a year ago if she could spend a whole year inside her home she would have fallen over laughing. But that is exactly what Marian did when the first lockdown was imposed in March 2020. "I had my letters saying I had to shield and I took it seriously," says Marian, a member of the Nottingham PF Support Group.

"My first trip out in over a year, apart from going to the freezer in the garage, was a visit to the opticians at the beginning of June. I was so excited! How sad is that?" she laughs. "I have been absolutely fine though, and kept safe and well. My husband Mike has been amazing, and I am very keen on sewing, so I've had plenty to keep me occupied."

But there have been sad times for the couple – Marian lost her 99-year-old mum, Carrie, just before lockdown and her sister has been very poorly. The couple have each lost a cousin during the past year. Mike also turned 80 and the couple reached their Golden Wedding Anniversary...and celebrated just with each other.

"Now I want to get out – I am nervous but enthusiastic. I went to my first WI committee meeting the other day, only six of us, socially distanced. It was great. And I'm having my hair done and a manicure and pedicure. Really looking forward to that!"

Community fundraising

Help raise vital funds this PF month

Get set for the return of Pulmonary Fibrosis Awareness Month this September!
We are dedicating the month to raising awareness and fundraising towards the vital work we do at Action for Pulmonary Fibrosis. We'd love you to get involved, in any way you can, to raise much needed funds to support patients and families affected by pulmonary fibrosis.

Create a Stir

Join us with your support group, family and friends or colleagues and host your very own drinks party. Bake or buy some yummy treats, pop the kettle on and welcome back members of your support group, work friends or catch up with friends and family while raising money and awareness during PF Month.

Sign up and we will send you a fun filled party pack with balloons, banners, collection boxes, coasters, and drink stirrers.

www.actionpf.org/get-involved/campaign/create-a-stir

Go the Distance

Whatever your distance, whatever your challenge, by asking friends and family to sponsor you, you will be making a real difference to people affected by pulmonary fibrosis!

Set your distance to your ability. Annette completed 100 laps around her garden to raise money for us. She's pictured here with her great nieces Lily and Isabelle. Annette told us,



"I've had pulmonary fibrosis for a few years now and two years ago I was told that maybe I had another year to live. But I'm still here! so I thought I'd raise much needed funds for research to help find a cure."

If you are a first-time runner, 5k is a good milestone to work towards. Maybe you would like to rack up those miles in steps and walk the distance? Maybe you would prefer to cycle or swim it? You could even take part in a sponsored family walk.

Whatever you do – your distance counts! Sign up and receive your free APF t-shirt.

www.actionpf.org/get-involved/campaign/go-the-distance

Take on a challenge!

As lockdown starts to ease, you or your family and friends might like to take part in an organised event. You can buy your own place in events across the country and fundraise for APF in September.

There are some great events taking place during PF Month, so why not sign up and fundraise for APF?

Every penny raised will help us continue our fight against this devastating disease, and provide vital information and support to families.

Thames Path Challenge

When: 11 – 12th September 2021
 Where: London to Henley-on-Thames

Take on the Thames Path Challenge following England's greatest river. The full route heads upstream from Putney Bridge past Hampton Court to Runnymede of Magna Carta fame, then past wonderful scenery all the way to Henley.

www.thamespathchallenge.com

Great Manchester Run

When: Sunday 26th September
 Where: Manchester

The Great Manchester Run is firmly established as Europe's largest 10k run. With live bands, DJs and multiple music zones adding to the amazing atmosphere, you will be sure to have a good time.

www.greatrun.org/events/great-manchester-run

Community fundraising

Art for APF's sake

Jenny and Louise Doran lost their mum, Anne, to IPF last year and wanted to raise funds for research to help others in her memory.

"Mum loved her artwork and liked nice paintings on the wall at home, so it seemed very fitting to hold an art competition to raise awareness and fundraise for the charity. I thought it would be a nice activity to do during lockdown in these difficult times, open to adults and children across the UK. We received many kind donations from various companies and individuals which we offered as prizes. A local artist and tutor selected winners."



Jenny and Louise raised £1,040 with their unusual idea. Why not get in touch to let us know about your fundraising ideas and exploits?

Sergio and his daughter Sophia completed their 10k challenge a few weeks ago in memory of their dear friend Iain Hainey – they have raised an amazing £3,483 and donations are still coming in. They even got support from an Espresso Kart for the event!



Sergio posted on Facebook: "When I was researching for the most appropriate charity, I was immediately drawn to APF because you place patients at the centre of your focus. No fancy frills, just genuine people with real passion, drive, and determination to support those suffering and also recognising that support for their family members is also crucial due to the ripple effect of such a deadly condition."

Give in Celebration

Do you have a birthday coming up? Are you fed up with getting socks or vouchers? Then donate your birthday to APF instead! Our Birthday fundraisers have donated over £45,000 so far! A very special thank you to all those that have donated their birthday.

www.facebook.com/fund/actionpulmonaryfibrosis



The APF Store is now open and online!

We have a range of branded items you can now purchase from our online store. From t-shirts to tote bags, when you shop at the APF Store, you are helping support more people and fund vital research.

www.actionpf.org/get-involved/resources-and-merchandise

Give our befriending volunteers a call

Our telephone support ambassadors are trained volunteers who all have a personal connection with PF and provide a listening ear by phone for patients, carers and family members over 18. They check that people are getting the support they need and signpost to other services.

Three of our volunteers talked to us about what the service means to them.

Stella Burnside told us,



“Having spent 40 years working in health and wellbeing services, it’s probably second nature to feel inclined to offer service where possible.

My diagnosis of IPF was quite a shock but, being reasonably well despite needing oxygen to move around, it was a logical step to answer to the call for support for the telephone service.

“It is very early in my volunteering but I have found that towards the end of the calls it is helpful to the caller to know that I am a person living with IPF.”

Tricia Kay was diagnosed with Hypersensitivity Pneumonitis eight and a half years ago, but there was very little literature to read about the condition. She explained how she was fortunate enough to be assigned a lovely lady called Susan who phoned her every Tuesday.



“I was able to ‘offload’ my questions and queries, however silly, and she would tell me where to get answers and alleviate my worries. Our weekly chats made a real difference to how I managed and coped with my lung condition. It was

for that reason that I decided that I would like to be able to do the same for someone else.

“You soon become friends and chat about other things and some of the health-related issues are relieved. I hope that I help my ‘friends’ as much as Susan helped me.”

Philip Williamson found being diagnosed with IPF a bewildering and traumatic experience.



“I had never heard of the condition and, having been very healthy and physically active throughout my life, found the diagnosis difficult to come to terms with, as did my partner, close friends and family.

“My consultant mentioned Action for Pulmonary Fibrosis and I visited the website. I found it encouraging and useful and felt a strong desire to support the charity and those living with the condition. The opportunity to volunteer for the Telephone Befriending Service seemed an excellent way of lending my support.

“The initiative is a splendid way for people affected by fibrosis to share their stories, to enjoy mutual support and encouragement, and to engage with someone who knows and can empathise with the impact of diagnosis and living with the condition.

“What is particularly rewarding, for both parties, is the chance to enjoy a chat, often in wide-ranging conversations – such as sharing information about our hobbies and interests and much more.”

You can contact us yourself to set up a call with a volunteer or health professionals and support groups can refer people, with their permission. Anyone who would appreciate a call should let the APF team know by emailing support@actionpf.org or by calling 01733 475 642

Sukh Kaur gives back to APF in memory of her beloved dad

“I owe so much to my parents - especially my father, Malvinder Rao, for his constant support throughout his life. When I found out about APF, it was wonderful to see a community dedicated to supporting everyone affected by pulmonary fibrosis. I wanted to do something to support it.”



“My dad was diagnosed with IPF in June 2017, aged 65. It was surreal as the diagnosis came days after my uncle passed away with the same illness. I realised the cycle was about to begin again; but this time up close. It was heartbreakingly as we knew what to expect.

“Dad was a headstrong and focused person - once he put his mind to something, he would not stop until his targets were achieved. With this tenacity, I have to say, my father lived a fulfilled life with many experiences only some of us can dream of achieving.

“He came to the UK in his 20s and started off on the factory floor of a manufacturing company. In 1996 he was offered a role to set up an office in Mumbai and without hesitating went for it. Mumbai became a second home and for that we will always be grateful.

“When the diagnosis came we knew dad would be disciplined about managing the IPF. At first, he was carrying out his normal routine, it was only when he started to cough he would feel exhausted and take it easy for the rest of the day.

“In January 2020 he became severely ill and went into hospital. The doctor said he was only now using 30% of his lungs and all they could do was make him comfortable as possible. His wish was to be at home when he passed as he especially wanted to spend as much time as possible with his grandchildren.

“My dad has been a pillar of strength in many of my tough times so when the time came for me to give him the support he needed, I didn’t hesitate. For a son or daughter experiencing the same thing, my advice would be to be present as much as possible and create memories. I understand it is hard, but believe me when I say the strength that you show really supports your loved one in their time of need.



“I wanted to support APF consistently in whatever way possible. I decided to support the charity through my matchmaking business, ‘Matched by Sukh Kaur’. With every client that books my services, a portion of the proceeds will be donated to APF and I will personally match each donation. This makes me happy - I can give a little back and support research to one day find a cure for IPF.”

Research update

Research update

As well as its devastating impact on people's lives Covid-19 has also affected pulmonary fibrosis research, with many studies being delayed or paused during these challenging times. However, the pandemic has also led to healthcare professionals and researchers rapidly developing new ways of working so that they can carry out research in innovative ways. The pandemic has shone a spotlight on respiratory health, and the need to better understand and treat respiratory illness has never been more pressing.

APF is part of a charities working group involved in a UK wide study (PHOSP-COVID) aimed at understanding and improving the health outcomes for patients who have had Covid-19. APF Trustee, Professor Gisli Jenkins at Imperial College London leads the interstitial lung disease section of this research.

Prof. Jenkins and his colleagues have recently been awarded a £2million UK Research and Innovation grant to investigate the long-term effects of Covid-19 on patients' lungs. They hope to better understand the extent of post-Covid-19 lung damage and scarring, identify who is more at risk and why, and monitor whether lung damage resolves, persists or progresses over time.

It is not yet known whether post-Covid-19 lung damage leads to progressive pulmonary fibrosis. A cutting-edge technology, called xenon magnetic resonance imaging (MRI) will be used to monitor participants over time. This technique has been pioneered by Professor Jim Wild and the POLARIS team at the University of Sheffield, who will be leading this part of the study.

MRI is an imaging technique that can be used to investigate how the lungs look (their structure) and how they work (their function). In xenon MRI, a person breathes in a harmless gas that has special properties, during an MRI scan. The gas is called hyperpolarised xenon-129. The inhaled gas travels into the person's lungs and then into the bloodstream in a similar way that oxygen does. The special properties of the gas mean that its movement within the lungs and into the bloodstream can be tracked. The information recorded during the scan provides very detailed information about the structure and function of the person's lungs.

The POLARIS team have previously used xenon MRI to better understand and monitor the progression of PF. Their research provides evidence that this technique can detect changes in a patient's lungs



APF Trustee, Professor Gisli Jenkins

before these can be picked up by some standard pulmonary function tests. Similar findings are emerging from the study of post-Covid-19 patients.

With the use of xenon MRI, the POLARIS team and researchers from the University of Oxford have been able to show that patients who reported persistent breathlessness post-Covid did indeed have persistent lung damage, despite standard clinical tests indicating that their lungs were normal. This is an exciting development because it suggests that disease progression can be detected early and accurately using this sensitive technique.

Dedicated research into Covid-19 is generating new knowledge and understanding of lung damage, which in turn may lead to benefits for the pulmonary fibrosis community.

Research update

Overwhelming response to our JLA survey

Our partnership with the James Lind Alliance and Imperial College aims to provide a top ten list of research priorities. These priorities will guide the future of PF research. The initial survey - to understand what matters most to the PF community - resulted in over 600 responses encompassing over 1,000 questions from patients, carers and healthcare professionals. A huge thank you to everyone who responded. We couldn't do this work without your support. We're also very grateful to our champions and partners who shared the survey far and wide.



Priority Setting Partnerships

Next steps:

- The 17 strong committee, made up of patients, carers and healthcare professionals will now complete work that will result in a 'long list' of questions that have not already been answered by research.
- The long list will be published later in the year, for the PF community to rank in order of importance. This is the next critical step that gets us closer to the top 10 unanswered research questions.

It is with deep sadness that we share the news that Ian Foote, a valued committee member who had IPF, sadly died earlier this month. Ian also helped to run the Northern Region IPF Support Group in Newcastle. Jenny Lynch-Wilson, Respiratory Nurse in Wales, says,

"Ian's passing is a very clear reminder that we need to work hard to improve outcomes for patients with PF. His presence at meetings will be missed."

Donations

Plan for the future

Help us change lives by leaving a gift in your will to APF.

With a progressive disease like pulmonary fibrosis, it can be harder to manage money matters as time goes by. Planning now for the future can make things easier later. We have useful information on our website on managing finances and preparing for the future, as well as a list of useful contacts to support you in your planning: www.actionpf.org

Making or reviewing your will as part of planning for the future ensures your assets go to the people or causes you care about. One of the ways you can help APF continue to be there for people affected by pulmonary fibrosis is by leaving a gift in your will.



Your gift – large or small – could help create a better future for people living with this devastating disease in years to come. You can choose for your gift to help fund support in the community, or fund vital research into the disease and new treatments.

To find out more about how your gift can change lives, please get in touch by emailing legacies@actionpf.org or call **01733 475642**

Donations



Give in Memory – Celebrate the life of someone you love

“It will be wonderful indeed if, in the fullness of time, no one ever again has to face such a struggle for life as that imposed by IPF.”

At a time of great sadness and loss, Ann Voigt felt it was so important to involve friends and family in raising awareness and funds for APF. When her beloved husband Michael died, Ann nominated APF as the beneficiary of donations made in his memory.

“My family and I were amazed and comforted by the number of people who were prepared to give their financial support. Several asked about the aims of the charity and I was able to explain that the foremost aim is to find a cure for pulmonary fibrosis.”

Setting up a Tribute Fund

When someone you love passes away, a tribute fund is a wonderful way of celebrating their life and all your memories. Action for Pulmonary Fibrosis works with **MuchLoved**, making it quick and easy to set up a personalised tribute page where you, friends and family can share photos, stories, music and memories.

You can even light virtual candles on anniversaries or times of reflection. It's easy for friends and family to donate to APF via the tribute page, raising vital funds in memory of loved ones towards life-changing research, support and campaigning.

For more information, or to request donation envelopes for cash collections, please email info@actionpf.org or call **01733 475642**.



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