Action for Pulmonary Fibrosis

Autumn 2020

Support Group News

Forget-me-not Christmas Appeal **Page 6**

APF Coronavirus Hub up-to-date info on our website

New APF raffle tickets inside! **Page 5**

Feature story

Stay safe and stay in touch

Steve Jones, Chair of APF, shares his thoughts on coping with the pandemic.

It is hard to believe that just eight months ago, most of us had never heard of Covid-19. Now it is all we seem to talk about, think about and worry about. Different levels of restrictions have been put in place in recent weeks across the UK and it may be that by the time you read this we could be back in a national lockdown. Our community has come a long way with shielding, but it looks like we are in for the long haul, with some difficult months ahead.

I lived with pulmonary fibrosis for eight years before receiving a single lung transplant in 2016 so I have been extremely careful ever since the first lockdown back in March. I am generally quite a positive person but recently, like many others, I have been feeling a bit anxious.

I am concerned about the risk of catching Covid-19, particularly as recent research led by APF trustee, Professor Gisli Jenkins, shows that pulmonary fibrosis patients are at greater risk of serious illness from Covid-19 than others. We all need to be very careful.

> ‘I am really proud of the way support groups switched to Zoom meetings but also how they try to keep in touch with those members who do not use the internet. As a community, we are now much more resilient than we were in March.’

Steve with his APF lanyard, see page 11 to order yours.

The anxiety for myself and my wife, Hilary, is also due to the uncertainty. When will life be back to ‘normal’? Will there be a vaccine? How difficult will lockdown be in winter? I am sure that many of you share these feelings.

But we have been here before and I feel sure that we can deal with this. When we were told to shield in the spring, many of us learned new ways to keep in touch with each other and with our families and friends. As we move into winter, don’t forget that APF is always here for you. (cont. on page 2)

www.actionpf.org

Support line **01223 785725**

Welcome from Debra

This has been the most challenging of times. Life has changed beyond our control, and as the Covid-19 pandemic continues through the winter months, we'll all need to dig deep into our reserves and look out for one another.

This has also been a time when the smallest moment can become more meaningful. A letter, call, or kind word, reminding us that we matter. I hope this Newsletter feels full of those little moments.

All of us at APF are acutely aware that the next few months will be challenging and we want you to know that we are here for you, offering support online, via email and by telephone.

Our telephone volunteers are reaching out to say we're here, you're not alone, and we can help to build a network of support around you.

In this newsletter you'll discover the support groups that, despite not meeting in person, are embracing traditional and new ways to stay connected **(page 8)**, while many fundraisers are stretching themselves in amazing and fun ways for a great cause **(page 4)**.

And what a fantastic collective effort for PF Month to raise awareness, funds and campaign for everyone's right to antifibrotics **(page 14)**! ●

Life is full of moments.
Thank you for sharing yours.

Debra Chand,
National Support Manager

(cont. from page 1) All the latest government information and other helpful tips are on our Coronavirus Information Hub **www.actionpf.org/information-and-support/coronavirus**. And remember, self-isolation does not mean being alone. If you would like a chat on the phone with one of our telephone support volunteers or with Lucy, our respiratory nurse, contact us on **01733 475642** or email **support@actionpf.org**.

Stay safe and stay in touch!

Steve Jones,
Chair of Action for Pulmonary Fibrosis

Volunteers provide a listening ear

Launched in June during Volunteers Week, our new peer support service offers a listening ear through the challenges of the Covid-19 pandemic.

Our telephone support ambassadors are trained volunteers who all have a personal connection with pulmonary fibrosis. They can provide a listening ear by phone for anyone with PF, carers and family members over 18. Two of our volunteers share their experience of this new support service.

Elaine's mum was diagnosed with PF in 2000 when information and support was thin on the ground. When her brother died and he was also found to have PF, Elaine came across Action for Pulmonary Fibrosis and was amazed at how much more was available.

"When the pandemic started I contacted APF to see what I could do. The training for the volunteers was great. Best of all was the mentoring offered after each call – I felt very supported throughout".

Susan is a nurse working at Papworth Hospital who also has a rare form of pulmonary fibrosis. Because she was shielding, she missed patient contact, so when APF Chair Steve Jones mentioned the peer support line Susan jumped at the chance to get involved.

"We were matched with patients which worked really well. One lady I spoke to has become a real friend. We compare notes about our experiences and it's good to connect with someone from a different part of the country. "It's a really valuable service, which is making a difference to people's lives. I think it's a fantastic thing to do and I hope we can get more people involved".

You can call us yourself to be matched with a volunteer for a chat or people can be referred by health professionals and local support groups, if they have permission from the person needing support. ●

Research

How you can influence research priorities

We know how important research is to patients and families. With your support, APF is committed to making further major investments in finding better treatments and a cure for pulmonary fibrosis. We also believe that you should have a say when it comes to choosing research priorities.

To make this happen we are partnering with Professor Gisli Jenkins from Nottingham University Hospitals Trust, and the James Lind Alliance (JLA). Gisli is a founding trustee of APF.

The JLA is a non-profit organisation that brings together clinicians, patients and carers in Priority Setting Partnerships (PSPs). We'll run a range of surveys and workshops that will identify 10 priority areas for research. This list will be used by APF to inform our research priorities and by other researchers to guide their work and support their funding.

You – our patients and carers – will be invited to get involved in this process and have your say on what is important to you in terms of diagnosis, treatment and care.

Our Pulmonary Fibrosis PSP Steering Group, a small group which includes clinicians, patients and carers, has just had its first meeting to set this process in motion. This is a very exciting project and we hope that as many of you as possible will be able to take part. Look out for further news and the ways in which you can get involved in our newsletter, on our website and on social media channels. ●

To learn more about the James Lind Alliance visit their website **www.jla.nihr.ac.uk**

James Lind Alliance
Priority Setting Partnerships

Partnership

APF partnership with Royal College of GPs

APF's Listen to Our Lungs campaign in PF Month 2019 has resulted in a fantastic partnership with the Royal College of General Practitioners (RCGP).

The 2019 campaign urged support groups, patients and families to contact GP surgeries with information and resources to improve awareness of symptoms and make links with local services. This was prompted by the unacceptably long waits some patients had for a correct diagnosis.

APF has now worked with the RCGP to produce a training module that will be marketed to 100,000 GPs about the signs and symptoms of PF as well as where to refer suspected cases.

Dr Helen Parfrey, APF Trustee and consultant respiratory physician at Royal Papworth Hospital says:

"Idiopathic pulmonary fibrosis (IPF) is an uncommon condition and an average GP practice may only look after a few patients with this incurable lung disease. We have worked with the RCGP to develop a state-of-the-art eLearning course. It follows through a typical IPF patient journey and highlights the clinical signs and symptoms, how to refer for investigations and anti-fibrotic therapies. This is a fantastic educational resource that we hope will empower GPs to have a better understanding of IPF and its current treatments as well as how they can best support patients living with this lung disease." ●

Thank you for Going the Distance for APF!

APF relies heavily on the funds raised by our incredible supporters. Unfortunately, due to the cancellation and postponement of several mass events such as the London Marathon and limits on other fundraising activities in the community, we have seen a drop in funding. Sadly, this comes at a time when APF is needed the most.

Throughout the next year we are developing a new research programme that could bring hope to people living with PF in the future. We are growing our support services to reach more people, including the launch of our Support Line Ambassadors earlier this year. And we continue to help make the voices of the PF community heard, raising awareness of this devastating disease.

We need your support now more than ever, so we would like to say a huge thank you to everyone who fundraised for APF during Pulmonary Fibrosis Awareness Month. You went above and beyond to raise vital funds to support our work. From running and cycling to baking and brewing, every penny raised from your PF month activities will help APF continue to be there for everyone affected by PF.

Catherine Traynor's mum was diagnosed with PF in 2019.Sadly, she passed away just before Christmas. With her three young boys, Daniel (7), Thomas (5) and Peter (3), Catherine took on the Go the Distance challenge. "I was keen to do something as a family. Sadly, their memories of my lovely mum will be limited given their ages but raising money for your charity gives us a positive focus and helps them remember her."

The family ran the equivalent of a marathon between them and, as the newsletter went to press, they had raised a magnificent £558!

Barbara O'Boyle chose PF Awareness Month to sign up for the Virtual Great North Run Half Marathon and raised over £2,600 for APF – an incredible achievement!
Her partner, David, is a member of the Leicestershire Support Group and Barbara said, "I am 'Going the Distance' to raise money for APF as my partner has had IPF for over six years. I would like to make a difference and raise awareness of this little known disease."

Malcolm Tait, a member of the Nottingham and Boston Support Groups, considers himself very fortunate to have received a single lung transplant 15 months ago. He said, "I like to support and raise awareness of the charity and the condition, help to raise funds for research which, in the future, will help others with IPF and support those living with it now." Malcolm set about reaching his goal of walking 5k around the footpaths of his village, which he dubbed A Journey Around Addlethorpe. Ever mindful of social distancing, he chose quiet footpaths where he enjoyed a peaceful walk and explored places he hadn't seen before, and enjoyed meeting local people new to him as everyone adjusts to the current situation by making use of the local footpaths for exercise. ●

Go the Distance – December Dash!

Don't worry if you missed the chance to sign up to Go the Distance or Create a Stir during PF awareness month, we'll be back in December with a festive spin. From 2nd November you can sign up to our Go the Distance December Dash or mulled wine and mince pie Create a Stir parties!

To sign up for more information email **fundraising@actionpf.org**

Go the Distance

Fundraising

Win with our new Christmas Raffle

Everyone loves a raffle, especially at Christmas! Inside printed versions of the newsletter, you'll find a book of 10 raffle tickets and a Freepost returns envelope for the 2020 APF Christmas Raffle.

Join in and help raise funds to ensure that everyone facing pulmonary fibrosis has access to the support they need and the chance of a better future. You could be in with a chance of winning some fantastic prizes whilst helping fund our vital work in support, research and raising awareness.

How to play

Tickets are £1 each. Send back your completed ticket stubs in the freepost envelope provided. To request more tickets please call us on **01733 475 642** or email **fundraising@actionpf.org**

You can either enclose a cheque with your donation payment (£1 per ticket) or donate via Bank Transfer BACS.

If you would like to pay by BACS, please email **fundraising@actionpf.org** quoting your full name, address and number of raffle tickets you would like.

Please send payment to:
Account Name: Action for Pulmonary Fibrosis
Account Number: 00023412
Sort Code: 40-52-40

Please reference your surname followed by 'RAF' when making the payment, e.g. 'SmithRAF'

Closing date: **16th December 2020**
Draw date: **18th December 2020**

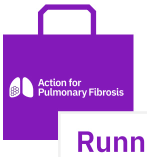
Full terms and conditions available on our website **www.actionpf.org**

First Prize
Dyson V11 cordless vacuum cleaner (RRP £499)

Second Prize
£300 cash

Third Prize
£100 in shopping vouchers

Fourth Prize
£100 of Next Christmas goodies



Runners-up
10 APF goodie bags

Fundraising

Flying high for APF

Would you, or your friends and family, like to experience the huge adrenaline rush of a sky dive while raising much needed funds to support people living with PF? The next APF tandem sky dive will take place in March 2021. To register your interest please email **fundraising@actionpf.org**

Forget-me-not Christmas appeal

This Christmas, we are inviting you to celebrate with APF's forget-me-nots. The festive season is often a time for reflection, celebrating those we love and remembering those we have lost. This year we are giving you the chance to remember loved ones and raise vital funds for Action for Pulmonary Fibrosis with glorious forget-me-nots.

Planting your APF forget-me-not seeds, either alone or with family and friends, is a chance to reminisce and celebrate happy memories. APF forget-me-nots can also be gifted to friends or family to show them you are thinking of them or to celebrate your friendship.

All funds raised will help us continue to be there for families living with pulmonary fibrosis and fund vital research giving hope of a better future for everyone affected by the disease.

The seeds will create a lasting and beautiful display of flowers that can be a wonderful reminder of the person or friendships you wish to celebrate. Seeds can be potted indoors during the winter months on a sunny windowsill or can be planted outside from May to give a splash of colour in borders. More information on how to get the best out of your seeds can be found at Gardeners' World **www.gardenersworld.com/how-to/grow-plants/how-to-grow-forget-me-not**

Seeds are available for a minimum donation of £5 per packet, and we will send your APF forget-me-nots straight to your door.

"I lost my grandad, Peter, to IPF in 1990. He was only 62 and we miss him every day. I was almost exactly the age that my daughter, Izzy, is now when he died. She knows all about her great-grandad and is looking forward to planting the APF forget-me-nots in a corner of our garden and helping support a wonderful charity." *Laura*

How to order your APF seeds

Visit **www.actionpf.org** to order your seeds online or pay by cheque and fill in the form below.

Help us grow our support and research with...

APF forget-me-nots

Name

Address

Postcode

Email

Phone

Please send me ______ **pack(s) of seeds** **(min. donation £5 per pack) Total** £

Please return using the **Freepost envelope provided**

☐ I'd like to pay by **cheque.**
Please make payable to Action for Pulmonary Fibrosis and enclose your cheque with this form.

Living with PF – keeping well in the winter

At APF we know that this winter will be like no other. Winter is always a challenge for people with pulmonary fibrosis and now we have the added threat of Covid-19. With something so worrying as this on our minds it is easy to forget the simple steps we can take to make life a little easier during cold weather. Thanks to Nancy Howard, Specialist Respiratory nurse at Worcestershire Acute Hospitals Trust, for her help in compiling this advice.

Planning ahead

If you have a long-term lung condition you should have a self-management plan. If you don't, talk to your GP or respiratory nurse about creating one.

By now most of you will have had the flu vaccination. If you haven't please contact your GP surgery. Everyone over the age of 65 and those with a long-term lung condition are entitled to free flu jabs. These are also available at your local pharmacy. Discuss with your GP or practice nurse if you are also eligible for the one-off pneumonia vaccination.

You can now use several apps and websites to order your repeat prescriptions online, either to collect at a pharmacy or for home delivery. Look at **www.nhs.uk** and search 'ordering repeat prescriptions online' to find out more.

You may be able to get extra help with fuel bills. Those born before October 5, 1954 qualify for the Winter Fuel Payment but there is other support, including Cold Weather Payments, Warm Home Discount and grants to pay off energy debts. Look at Citizens Advice at **www.citizensadvice.org.uk** and search 'grants and benefits to help pay energy bills' for more information.

Once Winter arrives

On days when you don't feel full of energy or motivated, be patient with yourself and remember to eat little and often throughout the day. Missing meals will only contribute to feelings of lethargy and tiredness. Don't wait to feel hungry before you eat, or thirsty before you drink.

Getting enough exercise, particularly during the pandemic, is a challenge. Be creative! Use the adverts on television or a particular time on the clock to remind you to stand up and move. Don't allow your partner or carer to prepare all the food and drinks, try to do what you can to keep active.

Wearing layers of clothing are best for keeping warm as they trap warm air and keep it close to your body. Invest in hot water bottles, blankets, socks or shawls and ideally keep your house and your bedroom above 18C consistently.

If you are on oxygen don't leave spare nasal cannulas in the car overnight as the plastic can split with the cold.

Avoid contact with people who have cold and flu symptoms. Keep a thermometer at home.
If you are feeling unwell with increased breathlessness, cough, high temperature, shivers or flu-like symptoms call your GP immediately.
If your lips are tinged blue where they would normally be pink and breathing is harder than normal **phone 111**. You know your condition better than anyone. If you are worried or feel you have deteriorated suddenly, **phone 999**.
That's what they are here for. ●

Keeping close for comfort

The PF support group network is hugely important to patients and families. It grew from a handful when APF began seven years ago to 75 just before the Covid-19 pandemic hit in March. Despite not being able to meet face-to-face recently, groups have found both new and traditional ways to stay in touch. At APF we can help your group stay connected and find inspiration from what others are doing.

From traditional to zooming marvellous

It sometimes seems as though during the Coronavirus crisis Zoom meetings have taken over the world. They are everywhere! Many of our support groups are using this technology to hold virtual meetings and if you would like to learn more about Zooming, John Conway, Chair of St George's ILD Support Group has produced a brilliant video on how to start **www.youtube.com/watch?v=Nl9jEcpRr3E**

If you are a patient or carer and your regular group isn't meeting online, you can join a Zoom meeting anywhere in the country. Take a look at our website for meetings near you – **www.actionpf.org** – or give us a call and we'll put you in touch.

Of course, we know that not everyone is online or comfortable with 'Zoom' but as the pandemic continues it is important to stay connected. There are many other ways that you can keep in touch including WhatsApp groups on your mobile phone, telephone buddying, emails and letters. There is always a way!

Do get in touch if we can help with any of the above: contact Gillian, Jo or Debra on **support@actionpf.org** or call **01733 475642**

We'd also urge health professionals to continue referring patients directly to APF and, of course, to local support groups during the Covid-19 pandemic. Papworth PF Support Group receives the highest number of patient referrals to their group each year. Congratulations to all involved in making that happen and if any support group is concerned that they are not receiving referrals please contact us at **support@actionpf.org** and we will help all we can.

And we can always post paper copies of this newsletter to any PF patient if they join our mailing list. It would be great if professionals and support group leaders could check whether people would like this service. All we need is their permission and address and we'll arrange it. And if any of your members would value a friendly listening ear, our growing team of telephone volunteers are also here to help.

Here are a few more 'staying in touch' ideas:

Gardening and optimism in Solihull

"These are very tough times for patients but we have maintained regular contact with our support group members. This brings its own challenges as we are a diverse group from many communities, many of which have been particularly hard hit by Covid. Zoom is simply not an option for most of our members but we have kept up a steady stream of emails with news, advice and information – some of it from APF's wonderful website. This has included suggestions about exercise, nutrition and even links to the RHS Chelsea Flower Show online, together with uplifting pictures of ILD Specialist Nurse Geraldine's own gardening triumphs! Whilst we don't expect to have face-to-face meetings this year, our aim is to keep information flowing and provide hope and optimism in these challenging times."

Karen Hughes and Geraldine Burge

A warm feeling from Northern Ireland

"We're in touch regularly by text, WhatsApp, email, telephone and our Facebook page and have a Zoom meeting every two weeks. The group is going strong and many of our members would miss our Zoom calls if we cancelled them. ILD nurse Pat Gorman, our group's 'star of the show', always tries to attend and is such a great support. I personally always get a very warm feeling and enjoy them very much.
Our members are fantastic."

Tom McMillan

A shout out for the WhatsApp group and Zoom calls run by the Exeter group

"I have to say how much it means to my wife and I to know there is a support network outside the wonderful NHS and our own fantastic family and friends. To see, hear and discuss issues within this group has given this illness an identity and a ready and willing place where we find mutual encouragement, advice and support.
Thank you all."

George

Above and Beyond in Leicestershire

"Our Zoom meetings are very popular and I've also been in touch with members via email and telephone. You don't want to bother people too much but sometimes a friendly phone call can be a real boost. The Leicester respiratory team have been fantastic and are not only promoting our virtual meetings but taking an active part and continue to refer new patients to us."

Alan Tratt

Supporting patients from the front line

Throughout the pandemic, the Leicester ILD team has supported patients as much as possible. In early March, when we halted face-to-face contact, we sent out letters and advice on shielding.
All clinic appointments were done by phone. Between consultant appointments the team made contact with as many patients as possible to ensure they were getting what they needed. We also arranged for patients to have medicines delivered to their homes.

'With the patient support group unable to meet, we set up a WhatsApp group and, when phoning patients, promoted the virtual support available.
We've also continued to refer to the group since lockdown began in March. Patients have found it really beneficial to have that support network. It has been incredible to stay connected to our patients during this time and very rewarding to be able to offer them support and updates about changes at the hospital.
It amazed me how quickly our patients adapted to everything, especially as a lot of them had never used Zoom before!
We are so proud of them all for staying safe.'

Kayleigh Hawkes, ILD Specialist Nurse and recent winner of a Cavell Star Award for exceptional care, from Leicester's Glenfield Hospital

Mindfulness

Now more than ever, our mental well-being is as important as our physical health. In this issue, our Health Tips focus on mindfulness, and how it can help to cope with anxiety. Sharla Elder, Respiratory Nurse at Western Sussex Hospitals Trust, shares her experience and advice, and offers a useful guide to practicing mindfulness.

I have been an ILD clinical nurse specialist for over eight years. I enjoy my role, especially being an advocate and providing a support network for my patients. As you may already be aware there are more than 200 types of ILD with the most common of them being pulmonary fibrosis.

Throughout the Coronavirus pandemic I have kept in contact with most of my patients who have been shielding. I know this has been a very worrying time for many of you – not seeing loved ones, unable to socialise, the feeling of being isolated but not wanting to 'bother' people, and appointments to see your health care professionals cancelled or changed. On top of this the knowledge that you must continue to be vigilant and maintain strict social distancing, despite restrictions being lifted for others, may be adding to your feelings of heightened anxiety.

Anxiety affects our thoughts, feelings and body in different ways. But they are linked and this can cause a vicious cycle of panic attacks, depression, fear and weight loss. This may lead to physical deconditioning and increased frailty which can reduce your quality of life.

Thoughts and feelings of anxiety include:

- Fearing the worse
- Feeling tense/nervous
- Dwelling on negative experiences or over thinking situations
- Feeling numb
- Feeling restless
- Inability to concentrate.

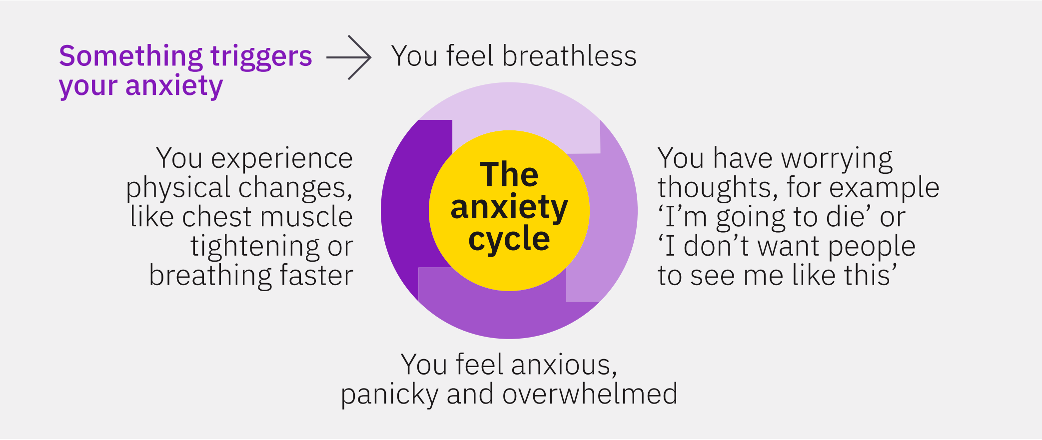
Physical symptoms of anxiety:

- Faster, shallow breathing
- Feeling sick
- Tightness or pain in the chest
- Feeling faint/dizzy
- Tense muscles/headaches
- Sweating
- Fast/thumping or irregular heartbeat
- Raised blood pressure
- Difficulty sleeping
- Churning in the pit of the stomach.

How mindfulness can help

As part of a recent scholarship I have been researching how mindfulness can help patients with pulmonary fibrosis reduce symptoms associated with anxiety. Mindfulness meditation can help break the cycle. The practice involves sitting silently and paying attention to the sensation of breathing. Concentrating on your breathing when you are short of breath may be difficult. So, another way to use mindfulness would be to focus on your feet (or any other part of your body) by anchoring them to the floor or chair and being aware of the sensation that you feel.

When you first practice mindfulness, it may be helpful to use an electronic app on your phone/tablet to help keep you engaged without your mind wandering. I found it easy to use an app to guide me and stop my mind wandering off.



Here are some comments from a few of my patients who have used mindfulness.

‘I have a greater acceptance of my respiratory illness, better awareness of breathlessness and control.’

‘Lower anxiety, less fatigued, improved quality of life and self-compassion.’

‘It enables me to have better control over with my pulmonary fibrosis.’

Mindfulness is not for everybody, but there is no harm in trying it. If you are suffering from ongoing anxiety and panic attacks please discuss this with your ILD Nurse/consultant or call the APF telephone support line on **01223 785 725**. You can also access free psychological support services via the NHS. Go to **www.nhs.uk** and search ‘psychological therapies’ to find out what is available in your area. ●

There are five easy steps to practicing mindfulness

1. Sit comfortably anywhere that feels quiet and calm to you.
2. Set a time limit; choose a short time to start with such as 5 to 10 minutes.
3. Notice your body. Sit with your feet on the floor, or if comfortable you can sit cross legged, kneeling or in any position you can sit still in for the full time.
4. Feel your breath. Follow your breath as it goes in and out. To breathe during mindfulness inhale deeply to allow your abdomen to move. When breathing out do it as slowly as possible until all the air is released. You can also try sighing out words or phrases about things that frustrate you.
5. If your mind wanders return your attention to your breath or your body.

APF Give me Space lanyards – a hit with Fife & Tayside

APF’s new Please Give Me Space lanyards and cards are already proving to be a big hit with patients and carers.

Maureen Ward, organiser of the Fife and Tayside Support Group says the lanyards have been a resounding success:

“We have had a great response to the lanyards. Our treasurer, Jim Pritchard and Secretary, Irene Taylor organised everything and sent them out to members. We also included a card reminding people that the support group is still there for them, along with contact numbers if they would like to talk to someone. One of our members wore hers when she went along to a hospice she attends. Not only did the staff think they were the nicest they had seen, another gentleman told her he had IPF and asked about the group. Now we have a new member. So, a big thank you – the lanyards are brilliant!

The lanyards are free to order from APF and will let others know that you have a serious lung condition or care for someone who does. We worked with patients and carers on the design and wording. The lanyards come with wallets and cards with three options, which can be inserted into the wallets and worn around the neck or held separately:

1. I have a serious lung condition. Please keep your distance. Thank you.

2. I find it hard to breathe, therefore I am mask exempt. Thank you.

3. I care for someone with a serious lung condition. Thank you.

They aim to give you added protection, security and confidence by asking others to give you more space to reduce the risk of Coronavirus infection. Where possible we would always advise you to wear a face mask or covering. However, we know that this may not be possible for everyone so for those who need it there is the option of the ‘mask exempt’ card.

You can order the lanyards online by visiting our website **www.actionpf.org** or email us at **info@actionpf.org** or call us on **01733 475642**. The £2 production cost is being paid for by APF but a donation is always welcome.

Research

Under the microscope

APF trustee Professor Gisli Jenkins goes under the microscope to talk about research developments over the past 20 years and prospects for the future.

> ‘Congratulations to Professor Jenkins on being awarded the prestigious European Respiratory Society Gold Medal for outstanding contributions to research into Interstitial Lung Disease, of which pulmonary fibrosis is the largest group.’

Q: When APF started seven years ago, you were asked if we’d ever find a cure. You felt there could be a major breakthrough within 10 years. Are you still hopeful?

A: We have had a number of breakthroughs already in the last seven years. These include fundamental scientific discoveries such as understanding the genetic basis of IPF, new treatments including Pirfenidone and Nintedanib, and ambulatory oxygen and pulmonary rehabilitation. We have also increased the number of PF patients receiving lung transplants. I am really optimistic that in the next seven years there will be even more!

Q: What has been the most significant development in our understanding of pulmonary fibrosis during your 20+ years as a researcher?

A: Without doubt the genetic basis for pulmonary fibrosis. This has provided insights into which cells in the airways and air sacs go wrong in IPF and why. It also helps us understand the interaction with environmental ‘triggers’ that lead to the development of fibrosis, why IPF occurs with advancing years and the molecular pathways which cause the scarring. This last point is critical in developing drugs to treat fibrosis. Genetics also enables us to target particularly high-risk individuals for earlier diagnosis and treatment, and increases the chances of a cure.

Q: A major development has been the introduction of two antifibrotic therapies for IPF – Nintedanib and Pirfenidone – and now Nintedanib has been approved for all progressive pulmonary fibrosis. How effective are these medicines at holding back the progression of the disease and do they prolong life?

A: This has revolutionised the management and study of pulmonary fibrosis for many reasons. We now know that PF is a disease that can be treated and there is now good evidence that these drugs prolong life. We know this for IPF but there is also emerging data that patients with other progressive fibrotic diseases are likely to benefit, although it is far too early to say whether the effect will be the same as for IPF. Unfortunately, these drugs are not the complete answer as they do not prevent the progression of the disease – they just slow it down. Some people find the side effects of the drugs difficult to tolerate too. Therefore, there is an urgent need to develop better drugs to either halt or better still reverse the fibrotic process.

Q: Currently, patients have to wait for anti-fibrotic drug therapy until their lung function gets worse… the 80/50 rule. Isn't it time that NICE ditched this rule? Patients in all other western countries can be prescribed these drugs as soon as they are diagnosed.

A: This is an unfortunate paradox. The NHS operates a healthcare system where choices have to be made in part on cost to ensure everybody has fair access to a full range of healthcare. Unfortunately, antifibrotic medicines are currently very expensive and therefore can only be prescribed to patients in later stages of the disease in whom there is evidence of 'cost effectiveness'. However, there is increasing evidence that these medicines also benefit patients in the earlier stages of disease and extend life. This, together with the ending of patent protection and competition from new, and potentially better, anti-fibrotic drugs give the hope that these treatments will become available to all patients in the not too distant future.

Q: We hear that outcomes for patients can be improved if diseases could be detected earlier. When people are diagnosed with PF they are often told they have had it for years – why can't we diagnose it and start treatment earlier?

A: We can diagnose IPF earlier and we can start treatment earlier. About 7% of people have what we call interstitial lung abnormalities (ILA), which we can pick up on high resolution CT scans. The problem is that only 15% of people with these will go on to develop progressive pulmonary fibrosis. The transition from ILA to IPF is also unclear. If we were to diagnose based on ILAs there is a risk of causing high levels of anxiety and we may end up treating people with drugs who don't need them and which may cause long term side effects. So, we need to be sure that we are only identifying people who need and are likely to benefit from specific anti-fibrotic treatment. At the moment we cannot do this but research is on-going and we may be able to in future.

Q: There has been a rapid growth in research on PF by university researchers and pharma companies. Can we expect new treatments in the next five years?

A: There are a whole range of anti-fibrotic drugs in the pipeline. Some of these involve repurposing drugs currently used to treat common conditions like diabetes, thyroid disease or high cholesterol. Others are completely new drugs that target specific molecules in biochemical pathways that lead to scarring such as autotaxin inhibitors and Connective Tissue Growth Factor antibodies. These drugs are currently being tested in clinical trials, which will confirm, or refute, their value in pulmonary fibrosis. ●

Patients and families are passionate about research. How can they help?

There are many ways people can help research. They can help by raising money for charities such as APF, writing to their MPs to explain that research is fundamental to developing new treatments and ensure that research is a government priority. More importantly they can participate in research through engagement with support groups, volunteer with charities to promote and attend public patient involvement initiatives as well as participating in clinical trials.

Pulling the stops out for PF Month

Pulmonary Fibrosis Awareness Month is a great opportunity to focus on fundraising, as you can see with our fantastic fundraisers on page four. APF Chair Steve Jones also wanted to do his bit. He lived with IPF for eight years and was fortunate to have a lung transplant four years ago. His contribution to Going the Distance in PF Month was to cycle 500 miles!

"Almost 90% of our income comes from fundraising activities by our wonderful supporters – patients, their families and friends.

I received a single lung transplant, so my lung function is only 50-60% of what it should be for some one of my age and build. Because of this, I ride an e-bike (but I try only to use the battery on hills!) My challenge was to ride 500 miles in the month of September around South Cambridgeshire, where we live. Taking one day off a week, that worked out at 20 miles every day."

Steve Jones, Chair of Action for Pulmonary Fibrosis

Shout Out success

Raising awareness of PF symptoms, treatments and research is just as important as fundraising. Pulmonary fibrosis accounts for over 1% of deaths in the UK and kills more people each year than either leukaemia or ovarian cancer. Despite this, very few people have heard of the disease.

Even getting through to GPs is difficult as they have so many illnesses and conditions to deal with, so we'd like to send a big thank you to Ian Foote, Northern Region Support Group organiser. He persuaded his local GP surgery to have a display of information about pulmonary fibrosis during PF Month. Thank you, Ian!

Politicians also have an important role to play in health policy, and APF produced a template letter to MPs to raise their awareness of the disease and specifically ask them to help secure universal access to antifibrotic drugs Pirfenidone and Nintedanib by ending the restrictions imposed by the National Institute of Health and Care Excellence (NICE).

Over 200 people downloaded the template letter to give a Shout Out to their local politicians, including Tony Brierley, pictured above with wife Sue, who has IPF. But then he took it a step further.

"Instead of just sending the letter to my local MP, I decided to contact him to request a meeting or call. I'm very pleased to report that James Grundy, MP for Leigh, and his parliament assistant Mark Cooper arranged a Zoom meeting with me.

"I explained all about Pulmonary Fibrosis and we discussed PF in general, the problems with access to anti-fibrotic drugs and how Covid is part of the problem now. James was very receptive and has kindly agreed to write to the government. He also explained the current difficulties of getting business done, raising questions etc in parliament due to the pandemic but is willing to pursue as soon as the circumstances allow."

'So that's a great big thank you to a local MP for responding, listening and getting involved. Let's see what we can do.'

PF month (cont.)

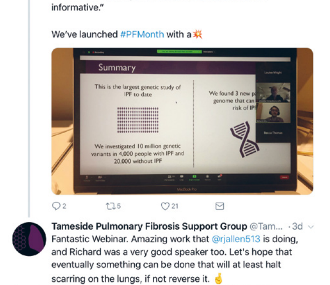
Janice joins forces

DJ Janice Long joined forces with APF during IPF Week in September, for the second year running. Janice is passionate about increasing understanding of the disease in memory of her late brother, television personality Keith Chegwin who sadly died in 2017.

"Before Keith was diagnosed none of our family had heard of IPF, it came as a total shock and everything happened so quickly. We had no idea how devastating this disease is or how quickly the disease would worsen. It was a terrible time for Keith and the whole family as we all tried to support him and come to terms with his declining health. I'm calling on GPs to think of IPF when people visit them with symptoms – to support this we all need to be more aware of IPF and seek help if we have an ongoing cough or breathlessness." Louise Wright, CEO of APF said:

> 'We are absolutely delighted to have the support of Janice Long. IPF is the forgotten lung disease and having the support of Janice helps to shine the spotlight on IPF and our 'Listen to Our Lungs' campaign. The challenge of living with IPF has been even more difficult in the last six months as the global pandemic has been a time of extreme worry and extra pressures. We can't thank Janice enough for her support.'

Webinar hits the spot



Action PF Charity @ActionPFcharity · 3d
We've run our first webinar led by @rjallen513! Over 135 attendees with over 50 questions from the audience!

"Thanks for making the research so accessible and informative."

We've launched #PFMonth with a 💥

Tameside Pulmonary Fibrosis Support Group @Tam... · 3d
Fantastic Webinar. Amazing work that @rjallen513 is doing, and Richard was a very good speaker too. Let's hope that eventually something can be done that will at least halt scarring on the lungs, if not reverse it. 🤞

Back in August APF-funded Mike Bray Research Fellow, Dr Richard Allen of Leicester University, ran a live webinar on the genetics of IPF. Richard has led the largest genetic study of idiopathic pulmonary fibrosis to date, helping identify changes in DNA that can increase the risk of IPF.

Almost 140 people attended the webinar, and Richard received over 50 questions from the audience! A comment from Tameside Support Group was typical of the responses we got:

"Fantastic webinar. Amazing work that Richard is doing and he was a very good speaker too."

If you missed it you can catch up on our website, where there is also access to the presentation slides. Look out for future webinars too. ●

People

New Research Officer joins APF

We are delighted to introduce our new Research Officer, Wendy Adams. Wendy will help drive APF's ambition to be a major funder of high quality pulmonary fibrosis research which leads to meaningful outcomes for our community. She studied Psychology as an undergraduate and has a PhD in Cognitive Neuroscience.

Wendy says, "I am passionate about enabling patients and carers to have improved access to, and understanding of, the latest research in PF. I have close family links to the disease and understand what it means to care for someone with a life-changing diagnosis."

Thanks again to all of our fundraisers who make it possible for us to recruit people who can help us make a real difference in the research world. ●

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 using the **Freepost envelope provided**

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

People

APF Chair appointed President of the EU-IPFF

APF is delighted to announce that Chair, Steve Jones, who has been on the Executive Board of the European IPF Federation since 2018, has recently been appointed President. Steve was diagnosed with IPF in 2008 and received a single lung transplant in 2016. He works tirelessly in the UK and Europe to improve the lives of PF patients and their families.

He said, "I am passionate about patient advocacy and raising awareness of pulmonary fibrosis, supporting patients and encouraging research to find a cure. In my position as President of the organisation, I would like to help make EU-IPFF stronger by:

- Building the capacity of our member organisations for us to become a really sustainable and effective network supporting pulmonary fibrosis patients and carers across Europe
- Advocating for better treatments and increased research investment, in partnership with doctors, nurses, researchers, the media and the pharma industry
- Raising awareness of PF and the needs of patients with decision makers, media and the general public.

Action for Pulmonary Fibrosis

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