New year, new hope

Steve Jones, APF Chair

It may be a little late but I really would like to wish you all a Happy New Year. For the first time in a long time, hope is on the horizon in the shape of the Covid-19 vaccine. Many of us will have had or will soon be getting ‘the jab’. This brings our PF community real hope of eventually getting back to some form of normality. Seeing our families without fear, meeting our friends freely and talking about something other than Coronavirus. However, as people in the extremely vulnerable category, we know that the jab isn’t a magic bullet. We will continue to be extremely careful for some time to come. And I think face masks and hand sanitiser are here to stay. But I think we can confidently say that there is light at the end of the tunnel.

During this very difficult year APF has continued to work hard for you and your families. Inside this issue you can read about our ambitious research plans, our campaigning to secure anti-fibrotic drugs for all and our work with GPs to improve early diagnosis. We can only do this with your help and we hope you will continue to support us through this new year.

Meanwhile, I wish you all the very best and look forward to the time when we can all meet again.

Steve gets his Covid jab.
Welcome

Welcome to APF Insider, our fresh new look magazine. This is an issue of ‘firsts’. In our first ever podcast, Sylvia reveals why making every day count matters when you have a life-changing condition. And APF’s new partnership with the James Lind Alliance, with our Hope for All Research Appeal, is creating your opportunity to help shape the future of PF research.

As vaccines bring new hope in these uncertain times, our Covid update responds to the many questions you have been asking us. We report on how e-learning is helping more GPs ensure earlier diagnosis, creative ways PF support groups are keeping us connected, and news of the first European PF Patient Summit this April. The first ‘Insider’, yes, but filled with the same passion to make a difference for anyone with PF. Debra Chand, National Support Manager

Information & support

Visit our website Coronavirus Hub

As we enter the second year of coping with Coronavirus, news about the epidemic and government advice is ever-changing. You can find all the latest information about the virus, and ways to support yourself and your loved ones, at our Coronavirus Hub – www.actionpf.org/information-and-support/coronavirus.

We have tailored national advice for those with PF, and as well as signposting people to reliable updates, it features helpful resources, ideas for keeping busy and tips to promote mental health and wellbeing.

Vaccinations and Immunisation has decided it is safe for people with long-term conditions and that people who are high-risk should be prioritised to get the vaccine early on. There is no reason to think the vaccination interacts with any medications. All approved vaccines have met strict standards of safety, quality and effectiveness. All approved coronavirus vaccines must go through clinical trials and checks as all other licensed medicines. Other vaccines are being developed and will be made available to the public once they’ve been thoroughly tested and shown to be safe.

Should I have the vaccine if I am immunosuppressed?

Although people on immunosuppressants will be offered the vaccine, scientists are not yet sure whether it will trigger the necessary ‘immune response’ in those with compromised immune systems. Until there is a clear recommendation, people on immunosuppressants are advised to continue to carefully assess the risks of mixing socially with other people.

Are there any side effects of the vaccine?

Most common side effects are feeling tired or achy, a sore arm and headache. Occasional allergic reactions can occur, but this is usually soon after taking the vaccine. As the vaccine is administered in a safe health care environment there will be facilities to treat allergic reactions.

Unsurprisingly, the main topic of conversation for many of us is the vaccine. Here are answers to a few of the most common questions we’ve been hearing. You can find more FAQs at the Hub.

Is the vaccine safe for people with pulmonary fibrosis?

Yes. The vaccine has been tested on people with long-term conditions and on people from a range of age groups, including older people. The Joint Committee on Vaccinations and Immunisation has decided it is safe for people with long-term conditions and that people who are high-risk should be prioritised to get the vaccine early on.

Research

A one-time opportunity for you to shape future research into pulmonary fibrosis across the world

Are you passionate about research into pulmonary fibrosis and ultimately finding a cure? We are calling on you to be pioneers in a truly unique opportunity to set the priorities for future research. If you have a lived experience of pulmonary fibrosis as a patient carer, relative or healthcare professional we need your help.

APF is partnering with Nottingham University Hospitals Trust and the James Lind Alliance to bring together clinicians, patients and carers to identify 10 priority areas for research. This list will be used by APF to inform our research priorities and by researchers across the world to guide their work and support their funding.

We are asking you to complete a survey about your experiences of the disease and any questions you may have that could be answered through research. This could be around diagnosis, treatment or your daily lives.

There is a copy of the survey and a Freepost envelope with this newsletter or you can complete it online. www.actionpf.org/research/james-lind-alliance

“"This is truly a one-off opportunity for us, as individuals, to help shape priorities for future research. Every single voice will be heard. We hugely value your experiences and this very ambitious project can’t work without your support and involvement. Thank you very much in advance. It is particularly appreciated during this challenging time.”

Louise Wright, APF’s CEO

The project is being guided by a Steering Committee including patients, carers and clinicians and Tom McMillian, a carer from Northern Ireland said: “I’m extremely proud and feel privileged to be a member of the James Lind Alliance (JLA) steering committee as a carer representative. My involvement with the steering committee has convinced me that the concerns, fears and uncertainties of carers everywhere in the UK will be addressed as never before. I am sure that the holistic approach being taken by the everyone involved will lead to improvements in patient care, carer support and help guide future research.”

Ian Foote, who runs the Newcastle PF Support Group commented:

“For most of us, this will be a once in a lifetime chance to put the diagnosis, treatment and care of pulmonary fibrosis at the front of the queue, thus hopefully our own experiences will benefit of others. The survey is simple and will be available on-line or in hard copy, with help available for on-line conversion for those without appropriate facilities. Let’s see if we can do everything possible to help future sufferers with this dreadful disease.”
Will you **Step Up** for APF this spring?

We need you to join our sponsored walk and help us conquer the UK this March!

*Did you know the UK coastline spans 11,000 miles?*

This makes an astonishing **25,000,000 steps**.

We are looking for fantastic APF supporters to pledge their steps and help us cover the distance over the month of March. By asking friends to sponsor you in your challenge, you will be raising vital funds to support our work.

It doesn’t matter how you complete your steps, you could saunter round your sitting room, hike up and down your stairs or even ramble through your local park – every step counts.

When you sign up, we will send you an APF t-shirt and be on hand to help you raise money to fund our work supporting the pulmonary fibrosis community.

At the end of the March, tell us how many steps you have achieved. We’ll add them up and see just how far we’ve walked.

So don’t delay, join our *Step Up* team today! Visit [www.actionpf.org](http://www.actionpf.org) to sign up.

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Dust off the sewing kit or dig out the knitting needles – it’s time to get crafty!

This spring we are looking for crafty supporters to join our *Made with Love* campaign and either hold a virtual afternoon of crafting or make and sell crafted goods. Collette Dobbin’s family wanted to do their bit to support APF and protect people against Covid. They came up with a plan to make and sell facemasks and so far, they have raised a fantastic £1,750.

Crafting is a fantastic and fun way to support APF. We’d love for the PF community to come together and craft this spring.

Whatever your craft, or if you are new to crafting, we’d love you to get involved. Visit [www.actionpf.org](http://www.actionpf.org) to sign up for your free pack or call 01733 475642.

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Football focus

Fundraising is vital to APF’s work, but raising awareness is important too. Leicester based Stoneygate Lions Under 13 Royals played a friendly in January in memory of Gordon Cotter, one of their player’s grandads who passed away on Boxing Day. The team wore their Action for Pulmonary Fibrosis away strip to help raise awareness with a whole new group of people.

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December Dash...

The Brierley family have long been supporters of APF and at Christmas they signed up to our December Dash! Dad Tony, eldest daughter Hayley and grandson Kalum did several laps of their local area in Greater Manchester whilst his youngest daughter collected cash donations from friends and neighbours during the challenge.

Not wanting to miss out on the fun, wife Sue, who has pulmonary fibrosis, did her bit socially distanced inside on her exercise bike and achieved a total of 36 minutes! Tony said:

“It was another day spent with inspirational people that I love the most, life affirming Christmas spirit and support from friends, family, strangers and even a corporate donation.”

In all they raised over £1,200, adding significantly to the huge sum they have raised over the past few years.

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Fundraisers of the Year 2020 – Tom and Una McMillan

APF is thankful for the amazing efforts of all our fundraisers – each person running, cycling, baking or selling raffle tickets to raise money for APF makes a huge difference to our work. Each year we recognise the efforts of a particular fundraiser or group, and we are delighted that our Fundraisers of the Year 2020 are Tom and Una McMillan! This couple, along with friends, family and the *Antrim Support Group*, have raised around £10,000 for APF during this incredibly challenging year. They have also tirelessly campaigned to raise awareness of pulmonary fibrosis.

Tom is leader of the Antrim Support Group in Northern Ireland and Una, who has PF, is heavily involved too.

Tom and Una really appreciated being recognised for their hard work. Tom said, “There is no doubt in my mind that enormous credit belongs to the people that we work with here in Northern Ireland. They are like family and best friends to us.

“It is a pleasure working with APF, you are all such caring people who have a real passion and drive. Una and I feel we could not be working with and for better people.”

We couldn’t continue our work without the fantastic support of our fundraisers like Tom and Una, with every £1 raised making a real difference:

- £50 could help us ensure people receive vital information about PF at diagnosis
- £300 could help fund phone calls to people living with PF to ensure they do not feel alone
- £1,000 could contribute towards essential research into the disease and treatments.

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Together we are stronger. Thank you for all your support in 2020.
Although IPF is an uncommon disease, it causes one in every hundred deaths. The average general practice will have three to five patients with IPF. We are looking at the dynamic relationship between these factors and what implications there may be for rehabilitation, treatment and management.

Travel and Attendance Awards
At APF, we know how important it is to support students and scientists. Our Travel and Attendance Awards enable them to share their research at conferences around the world by giving talks, presenting posters and networking. This year, we funded four awards although, of course, the conferences were ‘virtual’.

Wendy Adams, APF’s Research Officer, shares some updates on the research projects funded by the generous donations and fundraising efforts of APF’s supporters.

Research update
Dr Richard Allen, one of the recipients of APF’s Mike Bray Fellowship, has been continuing his research into the genetics of PF, along with collaborators across the UK, USA and Spain. Richard explained, “We tested over 10 million genetic variants for their association with disease progression and have identified regions of DNA that we can investigate further. This will hopefully help move us towards a more personalised and effective approach to treating PF.”

The researchers, led by Dr Olivia Leavy, also published a paper in the prestigious American Journal of Respiratory and Critical Care Medicine. This showed that a single genetic variant relating to mucus in the airways explains three times more risk of IPF than all of the other known common risk genetic variants combined.

Richard is also involved in a large national study investigating the long-term effects of COVID-19 on lung health.
Donate towards pulmonary fibrosis research today

Help us take the next big step towards finding a cure – donate to pulmonary fibrosis research today.

Research is hugely important to families affected by PF. Finding new treatments and learning more about the disease could help us find a cure for PF and bring an end to the devastation it brings to so many lives.

We have ambitious plans to fund ground-breaking research over the next three years that we hope will change lives and create a better future for everyone living with pulmonary fibrosis. Sheetal’s story explains why research is urgently needed now.

Unfortunately, Sheetal’s condition progressed very suddenly in April 2020, and she tragically passed away in May.

Following Sheetal’s death, Deepak, along with friends, family and colleagues, donated over £16,000 towards APF research. These funds will support vital work that will help create hope of a better future for everyone affected by this devastating illness.

Deepak says:

“It is critically important that something is done to make life easier for people living with pulmonary fibrosis. I wouldn’t wish what we have been through on anyone. This will be with us forever. That’s why we’re supporting APF research – we want funds raised in Sheetal’s memory to help families and to help find a cure. It’s what Sheetal would have wanted, and it helps us as a family to do something positive and to feel that something good can come out of what we have been through. Naisha is almost 11 now – she is old enough to remember her mum. She will want to do something positive, to raise awareness of pulmonary fibrosis and to make a change.”

Thank you to Deepak, Naisha and their family and friends for raising such an incredible amount towards APF research.

Sheetal’s Story

Sheetal was a devoted mother to her daughter, Naisha, and a successful property lawyer when she was diagnosed with a rare form of pulmonary fibrosis in 2015 at the young age of 38.

Sheetal suffered symptoms of pulmonary fibrosis, including a persistent cough, but was able to live a relatively normal life for five years following her diagnosis. Her husband Deepak explains, “Sheetal became breathless when on a long walk or climbing stairs, but she was able to continue working, do the shopping, daily chores and look after our daughter Naisha. She desperately wanted to live and be there for Naisha. “She was a very strong and courageous person – in fact, the bravest woman I’ve known. But it must have been incredibly difficult for her living in the knowledge that she had limited time – particularly as a mother who wanted to be there to see her daughter grow up.”
Support groups still going strong!

As the pandemic continues to affect our lives in so many ways, it’s fantastic to hear how PF support groups across the UK are still going strong and helping people cope.

More and more groups are holding Zoom meetings now, which are proving a popular way to keep in touch. Many were determined to get into the festive spirit at the end of 2020, despite restrictions, and held online Christmas parties, with quizzes and Christmas costumes to the fore.

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Feature story

Living with pulmonary fibrosis – Sylvia’s Story

Four years ago Sylvia was diagnosed with IPF. She is keen to share her journey with other patients and families in APF’s first ever podcast. Sylvia talked to psychologist Honey Langcaster-James. This is her story.

Living with IPF affected Sylvia’s mental wellbeing, particularly during the first lockdown in 2020. Here she talks about how the support of her family, getting outside and pulmonary rehabilitation has helped. She also mentions how her own coping mechanisms have helped her experience new ways of enjoying life and making every day count.

“I had my first scan in December 2016 and was referred to Glenfield Hospital in Leicester in February. My husband Pete and daughter Sarah came with me; we were left numb. It was very difficult to talk about how we all felt.”

“The consultant I saw was really positive, but it was a lot to take in. I was a bit panicked and hardly slept for weeks, I could only focus on what I couldn’t do and what I wouldn’t achieve. I am sure that was difficult for others to live with.

“A turning point was being told I needed to lose weight to help keep well (which I have) and to get on with my own shopping and not rely on other people. I got really cross and very down when pulmonary fibrosis patients were not recognised as vulnerable at the start of lockdown. It took seven weeks to get my letter.”

“We get a huge amount of support and information from the Northamptonshire PF Support Group which was set up and organised by Penny Tremayne. We have great speakers and we now have a Facebook page and a WhatsApp group so we can communicate with one another and get tips and advice from people who are going through the same things.”

Fatigue and coughing are my main problem and I really get worn out some days. Talking with friends and family during lockdown has been a blessing but talking for too long is difficult as it makes me cough so much. Simple tasks are more difficult now as it takes forever to do anything without resting in between and I get very frustrated. Pete is great but he can’t do everything so I have to leave things that I could do in a flash and be a lot more tolerant of myself.

“I am looking forward to seeing them and their families and giving everyone a hug. “I do have bad days but will continue to make every day count and that way there will be no regrets. I have much to be thankful for.”

You can listen to the podcast here www.actionpf.org/personal-stories/sylvia where Sylvia and Honey talk more about exercise, making preparations and staying mindful. The podcast has been supported by funding through a partnership with Boehringer Ingelheim.

Hope on the horizon

The antibiotic medicines Nintedanib and Pirfenidone have been game-changers for patients with Idiopathic Pulmonary Fibrosis (IPF). The anti-fibrotic drugs slow disease progression and can extend life by up to two years. Unfortunately, they are not currently available to patients whose lung function is below 50% or above 80%.

Under National Institute for Health and Care Excellence (NICE) rules, patients with other types of pulmonary fibrosis are also excluded.

Now, there is hope on the horizon for people with these other types of PF, which include conditions like chronic hypersensitivity pneumonitis (CHP), rheumatoid arthritis related interstitial lung diseases (RA-ILD) and asbestosis. Common forms of CHP include ‘farmer’s lung’ and ‘bird keeper’s lung’.

A clinical trial published in the prestigious New England Journal of Medicine in 2019 showed that Nintedanib slowed progression by 57% in these non-IPF types of pulmonary fibrosis.

This is great news and this new use of Nintedanib has been approved for use in the USA and Europe. NICE is currently considering whether it should be licensed for use in the NHS. APF has submitted a detailed paper to NICE, arguing strongly in favour of making the new treatment available in England.

We will do the same, in due course, in Scotland, Wales and Northern Ireland.

Our submission was developed with patients and carers and highlighted what it is like to live with these diseases (which is very similar to living with IPF) and the limitations of current treatments. We have been invited to take part in a hearing at NICE in June. NICE’s decision is expected in September.

APF Insider • Spring 2021

Feature story (cont.)
**Health Tips**

**Vitamin D – the Sunshine Vitamin – all you need to know**

You have probably seen talk in the media about Vitamin D and Coronavirus, and the impact lack of it may have on the lungs. Our thanks to Consultant Nutritionist, Michael Walne, for guiding us through the facts about this sometimes elusive vitamin. Michael has a particular interest in pulmonary fibrosis as his father-in-law, Johnnie, has IPF.

“Vitamin D is known as the Sunshine Vitamin because we can make it when the summer sun shines. Getting enough is essential – we need it not only for bone health but for a great many other processes too, including those within the lungs.”

Deficiency in Vitamin D can lead to fractures and porosity and there is a growing body of opinion that it can play a vital role in lung health. The vitamin is also involved in heart health, including blood pressure, and can influence cognitive and immune function. This leads us to ask about Covid. Unfortunately, it appears those who contract Covid with low levels of Vitamin D suffer more severely and are more likely to die than those with enough.

**So, let’s get enough!**

For many, sunlight alone is ineffective in producing sufficient levels of Vitamin D. There are numerous factors which prevent our bodies from making enough – not least the fact that in the UK we only have enough sunshine for approximately four hours a day, from April to September. UVB, the part of sunlight which makes Vitamin D, cannot pass through haze, clouds, air pollution, light clothing or glass. Sunscreen of SPF8 or above also stops it getting through as normal. A person’s age and weight can also negatively impact their ability to maintain sufficient levels – the older and heavier you are the less Vitamin D you will make.

Vitamin D levels fluctuate from person to person but most experience low levels in the winter months and some even during the summer months. What we must do is make the most of the sun that we have; 20 minutes of sunlight with hands, arms, and face uncovered helps enormously but ensure you do not get burned. Burned skin does not make Vitamin D.

**It is important here to recognise that the anti-fibrotic drug pirfenidone can cause photosensitivity and those taking it are recommended to wear factor 50 sun cream and cover up all year round.**

Can food help? The short answer is yes, however this is not a simple answer either, because there are different forms of vitamin D. Some are more abundant, some more potent and there is huge variation in amounts. So, let’s simplify this, using average content, to create a top five:

<table>
<thead>
<tr>
<th>Food</th>
<th>Amount per portion (standardised to mcg D3)</th>
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<tbody>
<tr>
<td>Oily fish*</td>
<td>(140g)</td>
</tr>
<tr>
<td>1 egg**</td>
<td></td>
</tr>
<tr>
<td>Lamb</td>
<td>(230g)</td>
</tr>
<tr>
<td>100g VitD mushrooms</td>
<td></td>
</tr>
<tr>
<td>Beef</td>
<td>(230g)</td>
</tr>
</tbody>
</table>

*not farmed **organic, free range

If you can eat about 25 mcg a day from these foods, levels will probably improve to optimal. If not, you need a vitamin D supplement. Irrespective, I strongly advise everyone to have their levels tested. For optimal health, you want levels above 50nmol/L-1 (between 50-100nmol/L-1 is an optimal range). Above 120nmol/L-1 adverse effects are more likely. You may wish to make dietary changes first, and maintain these for about a month, and then get tested. If levels are still not above 50, supplements are advisable. Please also consider that various factors can reduce levels, such as stomach acid-lowering medication, antibiotics given to treat tuberculosis and those given to treat inflammation seen with PF. Also, if you suffer from certain medical conditions relating to kidney health, parathyroid issues and sarcoidosis, seek medical advice before supplementing with vitamin D.

If you are high-risk COVID category, you can obtain vitamin D supplements via the NHS: www.nhs.uk/conditions/coronavirus-covid-19/people-at-higher-risk/get-vitamin-d-supplements/ Speak with your GP about any concerns you have.

**APF raffles**

**Christmas winners**

Thanks to everyone who bought tickets in our Christmas raffle – we raised over £1,300!

Our winners included:

- Mrs M Davies: Dyson V11 vacuum
- Lisa Stockton: £300 cash prize
- Mrs A Rayner: Gift hamper

If you missed out, don’t worry – the spring brings another chance...

**Spring raffle**

**It could be you!**

Inside this newsletter you will find tickets for the APF Spring Raffle. There are some fantastic prizes to be won! Tickets are £1 each and come in books of 10.

To play, please return your completed ticket stubs in the freepost envelope provided and follow instructions below to make payment. To request more tickets please call us on 01733 475642 or email fundraising@actionpf.org

**To pay by cheque:** Please make cheques payable to Action for Pulmonary Fibrosis and return with your tickets.

**To pay by BACS:** 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 in books of 10.

[![Raffle tickets](Image 594x1 to 1192x564)](Image 594x1 to 1192x564)

**First Prize**

- £500 cash

**Second Prize**

- Dyson Supersonic hair dryer (worth £300)

**Third Prize**

- Yearly magazine subscription

**Fourth Prize**

- Retail vouchers

Drawing date: 1st July 2021
Closing date: 2nd July 2021

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

Spring winners

- Mrs M Davies Dyson V11 vacuum
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If you missed out, don’t worry – the spring brings another chance...

There are some fantastic prizes to be won! Tickets are £1 each and come in books of 10.
An invitation to the first ever European Pulmonary Fibrosis Patient Summit

The first European Pulmonary Fibrosis Patient Summit will be held virtually from 23-25 April 2021. It was originally planned as a face-to-face summit in Poland last April but had to be postponed because of the Covid pandemic.

There is a really exciting programme on offer, including news on cutting-edge research such as new developments in antifibrotic therapies as well as sessions on person-centred care and advocacy. You don’t have to attend all sessions – you can dip in and out as you like. There will be lots of opportunities for patient and carers to exchange views and ask questions of researchers and health care professionals.

If you would like to attend the virtual Summit, just register on the EU-IPFF website [www.eu-ipff.org](http://www.eu-ipff.org).

The Summit is organised by the European Pulmonary Fibrosis Federation (EU-IPFF), which aims to raise awareness of pulmonary fibrosis and improve care and treatment across Europe. EU-IPFF is an umbrella organisation of 21 patient organisations from 15 countries across Europe. APF was one of the founding members of the federation and APF Chair Steve Jones is currently President of EU-IPFF.