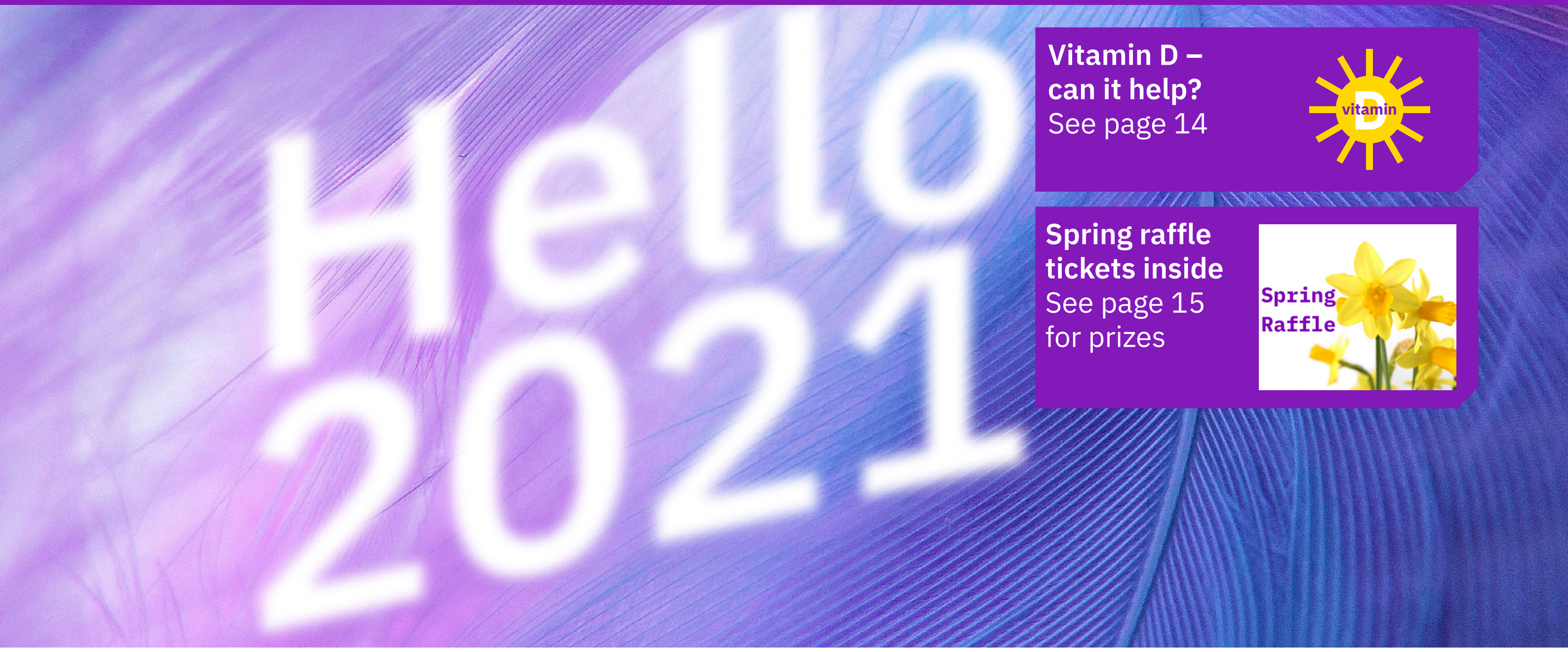
Action for Pulmonary Fibrosis

Spring 2021

APF Insider

Support — Research — Educate — Campaign



Vitamin D – can it help?
See page 14

Spring raffle tickets inside
See page 15 for prizes

Spring Raffle

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.

Hope for All Research Appeal

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

Full story page 8

www.actionpf.org

Support line
01223 785725

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 for promoting mental health and wellbeing.

APF also continues to provide help through its Support Line on **01223 785725.** Call us if you want to speak about health issues or chat with one of our telephone volunteers, who all have experience of living with pulmonary fibrosis.

Coronavirus and people with APF

Action for Pulmonary Fibrosis

Here you can find all you need to know about the virus and ways to support yourself and your loved ones whilst in self isolation. We're a community. We're in this together.

actionpf.org support line 01223 785725

Coronavirus Hub special

1

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. 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. ●

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** to sign up. ●

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** to sign up for your free pack or call **01733 475642**. ●

Supporter Lauren's beautiful crafts are helping APF.

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. ●

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. ●

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. ●

Together we are stronger.
Thank you for all your support in 2020.

APF’s partnership with GPs reaches out to Europe

We recently reported on the e-learning training that APF developed in partnership with the Royal College of General Practitioners. This was produced in response to the findings of our 2018 patients survey, which showed that 37% of IPF patients were mis-diagnosed by their GPs.

The study module, which takes just 30 minutes to view is free to all health care professionals (HCPs) in the UK. The aim is to help HCPs to recognise the signs and symptoms of the disease and to learn about available treatments referring suspected cases.

The training is now well established and APF trustee, Dr Helen Parfrey, from Royal Papworth Hospital, presented the module at the recent European Respiratory Society Congress to a virtual audience of over 1,500 people. The Congress is a showcase for excellence in respiratory medicine.

Helen explained why it was so important to educate GPs about the disease:

> “Although IPF is an uncommon disease, it causes one in every hundred deaths in the UK. The average general practice will have three to five patients with IPF, yet we know that over half of IPF patients have waited more than six months to be diagnosed, with 20% taking over two years.”

The problem is not confined to the UK, as these patient quotes from the presentation show:

> “I was angry and upset; it took over two years to get a diagnosis and I felt none of the doctors cared.”

Patient, Italy

> “The doctors themselves give the impression that they don’t really understand.”

Patient, Spain

Earlier diagnosis improves access to specialist services, including anti-fibrotic therapies, which slow disease progression and may improve survival rates. It also enables patients to take part in research and clinical trials.

86 GPs have completed the programme since September. Commenting on the module, Dr Catherine Traynor, a GP from Lancaster, said,

“I think this module is excellent. It delivers some pertinent and practical points. For example, I like the fact that when talking about IPF not being common it actually says how many patients in a practice might have it.

“It is concise but informative and I like the reference to NICE guidelines within the module. Another important area is around coding. It’s so important to code this correctly in patients notes so they are appropriately highlighted. This is not always something that’s emphasised in other learning modules.” ●

Research update

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.

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’.

Dr Owen Tomlinson and Dr Richard Hewitt attended the American Thoracic Society Conference. Richard is a specialist registrar based at the National Heart and Lung Institute at Imperial College London. His PhD research focuses on the mechanisms driving IPF.

“My research has a specific focus on the cells which line our airways and our immune cells – areas which have been relatively unexplored in IPF. I work in a laboratory using cutting edge technology, including in-vitro cell culture models, microscopy techniques and RNA-sequencing, to better understand how these cells differ in IPF patients.”

Owen is a postdoctoral associate research fellow at the University of Exeter. He is an exercise scientist and is looking at how physical activity can enhance fitness and quality of life in people with respiratory disease.

> “This is the first time that activity, breathlessness and fitness have been assessed simultaneously in a group of people with IPF. We are looking at the dynamic relationship between these factors and what implications there may be for rehabilitation, treatment and management.”

Rachele Invernizzi and Jonathan Miles took part in the European Respiratory Society (ERS) international congress.

Rachele is a final year PhD student at Imperial College London. Her research focuses on the role of microbes and the chemicals produced by cells during metabolism in the development of progressive PF. Her research is supervised by APF Mike Bray Fellow, Dr Phil Molyneaux.

“The conference provided a great opportunity not only to discuss my findings with international researchers in the field but also to connect with other research groups and enquire regarding future postdoctoral positions.”

Jonathan is a PhD student at Imperial College London investigating the possible causes of chronic cough.

“I presented evidence that suggests that excess oxidative stress within the lung could be contributing to chronic cough. There was a lot of interest from other academics in my poster, both during the event and via email afterwards, which is highly encouraging.” ●

Mike Bray Fellowship news

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.

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."

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.

Be a part of the change – donate towards research today

We have already made great strides in pulmonary fibrosis research, but we need to increase our research programme to ensure in the future, families will not need to suffer as Sheetal's has.

It will cost over £1 million to fund our ambitious plans that will help find new treatments and strengthen our chances of finding a cure. But we can't do this alone.

If you would like to take action and help us in our mission to find a cure to pulmonary fibrosis, please donate towards our Hope for All Research Appeal today.

Thank you

To make a donation please visit **www.actionpf.org/hopeforall** or complete the form below and return with your cheque made out to 'Action for Pulmonary Fibrosis' in the freepost envelope provided.

Name

Address

Postcode

Email

Phone

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

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

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

Support

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.

You can find details of all the support groups on our website at **www.actionpf.org/information-and-support/find-a-support-group** or drop us a line at **support@actionpf.org** with your postcode and we’ll point you in the right direction.

Wonderful work in Wales

A big shout out and thank you to the **Swansea PF Support Group** who continue to support the work of APF. Pictured are Chair Maggie Crawford with group members Fran George and daughters Rosemarie, Kathryn and Victoria who between them have raised over £1,500 through PF Month donations and a charity concert. Fran, whose husband died with IPF, has continued to be a staunch member of the Swansea group.

The group also held their first Zoom meeting in December. They had been hoping to meet in person but with the increased incidence of Covid-19 felt it would not be sensible or safe. Treasurer David Rees arranged the Zoom to help members stay in touch and support each other and nine members joined in. Maggie Crawford commented, “It was so good to see friends again and have a chat. It was very informal and we were glad to be joined by Dr Kim Harrison, retired consultant chest physician at Morrison Hospital. Many of us are so grateful for the special interest he had in treating patients with IPF.”

Sheffield Question Time

One of the big challenges faced by the **Sheffield PF Support Group** has been keeping in touch with health care professionals at the Northern General Hospital. Clinic appointments have been scaled back considerably and even telephone consultations have been much less frequent than normal.

“We know just how pressured the doctors and nurses are but there was something being lost through our inability to see our medical team on a regular basis,” said the group’s vice chair Gordon Harrison.

“After speaking with the specialist nurses at the clinic we came up with the idea of hosting a BBC Question Time style event by Zoom with a panel of medical experts.”

The panel included ILD consultants, Dr Stephen Bianchi and Dr Chris Barber and specialist nurses, Dawn Weston, Sue Miller and Billie Jean Walsh. Although they weren’t able to handle personal questions, there were many general queries which could be tackled. Questions were submitted a week before the event and thirty people took part. The subjects ranged from current outpatient clinic procedures, Covid-19 impact and research to treatments, medication and transplantation.

“The feedback was instantaneous and unanimously favourable: emails and WhatsApp notes arrived thick and fast! The panel said that they were pleased to have the opportunity to get some key messages across to a wide audience of patients and carers, while the members felt that it had been enjoyable and worthwhile as their concerns had been addressed by the very people they would have seen face-to-face under normal circumstances.”

The Sheffield group is planning to build upon the Question Time concept, as a very simple but effective way of keeping connected and above all else, providing reassurance, in these uncertain times.

Support (cont.)

Action Group for Scotland

Our new Scotland PF Action Group is aiming to increase support for people with PF throughout Scotland. Key steps this year will be to register with the Scottish Charity Regulator (OSCR), hold a virtual event for health professionals, patients and carers, and raise more awareness and support, including through new support groups.

If you are interested in being part of this exciting work contact **debra@actionpf.org** – we’d love to hear from you!

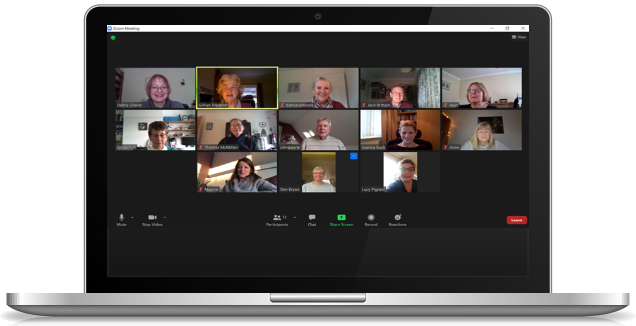
Carers Focus Group

The PF Carers Focus Group hosted by APF meets every six weeks as a support group for carers and to give valuable insight into the challenges of supporting someone with PF and what can help. The members have helped us to develop new initiatives such as the ‘Give me space’ lanyards and a new leaflet for anyone who is newly diagnosed.

With their help we have also produced a new TV screen advert which can be displayed on monitors in hospital or GP waiting rooms to advertise local support groups. Thanks to the Kent support group for suggesting this initiative. If you would like a copy of the advert (pictured below), which has an editable space for you to pop in your group’s contact details, dates or message contact **info@actionpf.org**. ●

Dee Bryan commented”

“Thank you APF! Your support and energy to help those of us dealing with this awful condition and give carers a voice has been invaluable, especially in this difficult year.”



Don’t face pulmonary fibrosis alone

If you have pulmonary fibrosis (PF) then we are here for you.

We provide information on living well with PF and can link you to support groups, peer volunteers and a specialist nurse.

We also fund research to bring hope and a cure for more than 70,000 people with PF today.

Action for Pulmonary Fibrosis

Registered charity: 1152399

For more information:

Support Line: 01223 785 725
Email: support@actionpf.org

www.actionpf.org

Your local PF Support Group:

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.

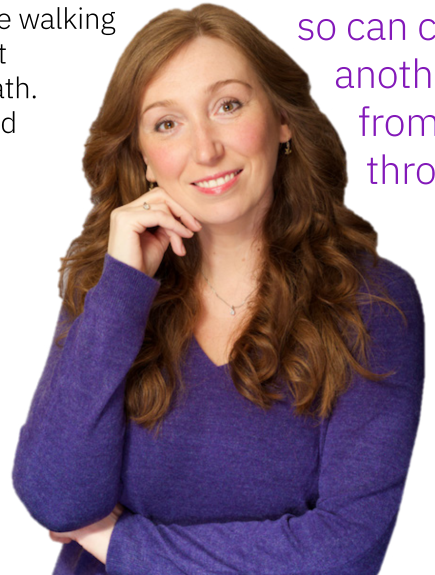
"The consultant I saw was really positive, but it was a lot to take in. I was a bit panicked and hardly slept for weeks, I could only focus on what I couldn't do and what I wouldn't achieve. I am sure that was difficult for others to live with.

"A turning point was being told I needed to lose weight to help keep well (which I have) and to get on a pulmonary rehabilitation course. The RESTART team in Northampton were brilliant. They got me walking outdoors again and focusing more on what I could do – and it was ok to be out of breath. They helped me to completely lift my mood and gave me a huge amount of support.

"I was coping well, until the first lockdown set in. Not seeing my daughter, son Peter, and especially my grandchildren has been painful, as it has for so many. FaceTime, however, has been such a bonus! Not being able to go out at all was awful but necessary, but eventually being able to go out for a walk with Pete and the dog has made a big difference to my mental health.

"My daughter Sarah has been a rock during lockdown. She did a shop for us every week and delivered it to us even though she has a husband and three children herself. Any bits and pieces were supplied by our local corner shop but I really wanted to do 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 can communicate with one another and get tips and advice from people who are going through the same things."



Honey Langcaster-James

Feature story (cont.)

"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 do know that I am so lucky to have such a supportive family. Pete is a tower of strength and videoing with Sarah and FaceTime with my son helps to give us some laughs through this madness. 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 antifibrotic 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.

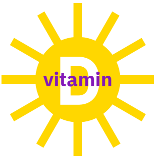
Now, there is hope on the horizon for people with these other types of PF, which include conditions like chronic hypersensitivity pneumonitis (CHP), rheumatoid arthritis related interstitial lung diseases (RA-ILD) and asbestosis. Common forms of CHP include 'farmer's lung' and 'bird keeper's lung'.

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. ●

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 porosis 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.

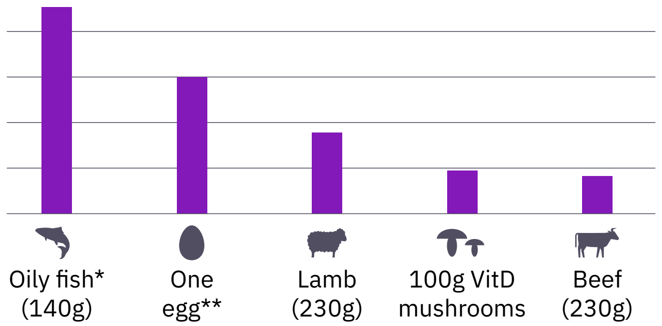
Vitamin D levels fluctuate from person to person but most experience low levels in the winter months and some even during the summer months. What we must do is make the most of the sun that we have; 20 minutes of sunlight with hands, arms, and face uncovered helps enormously but ensure you do not get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

Top five food sources
Amount per portion (standardised to mcg D3)



*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.

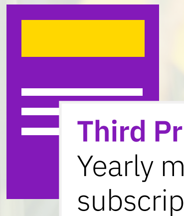
To pay by BACS: Please send payment to
Account Name: Action for Pulmonary Fibrosis
Account Number: 00023412
Sort Code: 40-52-40
Please reference your surname followed by RAF when making the payment, for example 'SmithRAF'

Closing date: **1st July 2021**
Draw date: **2nd July 2021**

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

First Prize
£500 cash

Second Prize
Dyson Supersonic hair dryer (worth £300)



Third Prize
Yearly magazine subscription

Fourth Prize
Retail vouchers

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**

Event

An invitation to the first ever European Pulmonary Fibrosis Patient Summit

European PF Patient Summit **2021**
Patients Driving Change

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**.

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. ●

Action for Pulmonary Fibrosis

General enquiries
01733 475642
info@actionpf.org

Action for Pulmonary Fibrosis
Stuart House, St John's Street,
Peterborough PE1 5DD

www.actionpf.org

Registered charity 1152399 in England and Wales

Registered with FUNDRAISING REGULATOR

This newsletter has been produced with the support of Boehringer Ingelheim

Boehringer Ingelheim

Support line
01223 785725