

Organ donation law in England is changing



A change in the organ donation law from Spring 2020 could herald new hope for patients with pulmonary fibrosis. Under the new law, all adults in England will be assumed to have agreed to be an organ donor, unless they have recorded a decision not to donate.

There is currently a desperate shortage of lungs for transplantation in England with just 164 transplants last year - only around 70 of those were for patients with PF.

Action for Pulmonary Fibrosis welcomes this change but Chair, Steve Jones, warns:

“Despite the new ‘opt out’ system, when a person dies their body becomes the property of their next of kin who must still give permission for organs to be used. At this awful time, if families don’t know a loved one’s wishes permission is often denied. Let’s spread the word about this change in the law and encourage friends and family to make sure loved ones know if they are happy to donate organs after death. You can record your agreement at www.organdonation.nhs.uk.”

Steve, who received a single lung transplant in March 2016, says “Having a lung transplant is a major undertaking, but it can improve your quality of life and extend your life, as it has done for me.”

We talk to Alan Wheeldon and Andy Bright about their experiences of having a lung transplant, on page eight.

Flying the flag at Great Manchester Run

APF runners will be flying the flag for the third year at the iconic Great Manchester Run on May 24th, raising awareness of pulmonary fibrosis as well as much-needed funds.

We still have a few charity places left for both the 10k and the Half-Marathon. You’ll be part of an enthusiastic and welcoming team and, on top of helping APF, you’ll also enjoy a great day out!

If you have family or friends who would like to take part and run in APF’s colours please contact Sharon Moon at fundraising@actionpulmonaryfibrosis.org





Welcome

I am delighted to join APF as your new support manager. It's been wonderful to meet groups around the country, and I can't wait to see more of you this year – what a committed bunch of people! Coming from a health charity background, I am passionate about the positive difference that good support can make to patients and families. By providing a warm welcome and support from others who understand, groups are changing lives and helping to overcome the fear and isolation that follows a diagnosis of PF.

Having over 75 support groups across the UK, reaching over 3,000 people, is something we can all be proud of. But we know that many more people don't know about groups or can't get to one, and we are determined to change that.

Enabling patients to drive change is central to everything we do at APF. We want to listen even more to the issues that matter most to you and ensure you are involved in campaigns and research. On this theme it's exciting that the first ever European IPF-PF Summit will be held in Poland this year. APF is sponsoring up to 20 patients and carers to take part.

Whether in person at events, or online in social media, your voice will help to bring hope and a brighter future for everyone living with PF. I can't think of anything more worthwhile, and look forward to working with you in this endeavour.

Debra Chand
National Support Manager

Chair's Report



Steve is pictured with his trusty e-bike. Find out more on page 11

Over the last decade we have seen marked improvements in pulmonary fibrosis care. Back in 2010, there were almost no support groups, only a few specialist hospitals and no anti-fibrotic drugs. Now, we have over 75 support groups across the UK, about 30 specialist interstitial lung disease centres and two anti-fibrotic drugs, which can slow progress of the disease and extend life. There are new drugs in the pipeline, which offer hope for patients living with IPF and other forms of the disease.

As we enter the new decade, Action for Pulmonary Fibrosis plans to expand its work to give even better support to patients and carers and invest further in research to find a cure.

Last year we started to implement our strategic plan (2019-24), which will strengthen our programmes of support, education, awareness raising, campaigns to improve treatment by the NHS, and research to meet the needs of patients and carers.

None of this would be possible without you - our amazing supporters and fundraisers. We are a patient-led charity and we try to ensure that everything we do addresses your priorities. Please be sure to let us know if there is anything you think we can do better!

Steve Jones

Steve has been Chair of APF since 2017. He was diagnosed with IPF in 2008 and received a lung transplant four years ago. He is passionate about raising awareness of pulmonary fibrosis and supporting research to find a cure.

Spotlight on Antrim



Organisers Tom and Una McMillan reflect on how the first Northern Ireland group has grown.

“Our support group is very patient-focused and we all work hard to help and support one another. We are also very active in raising funds and awareness of the disease. I feel extremely proud to have played a part in the advances that the group has made since it began in 2016. In those days it was unlikely that anyone had ever heard of pulmonary fibrosis. Today, through the hard work of everyone associated with our group, there is a better understanding of PF throughout Northern Ireland. We are on Facebook and Twitter and help people across the country; in fact, we have members who make a four-hour round trip to meetings!

“The group was set up by two very dedicated professionals - Dr Eoin Murtagh and Pat Gorman, our ILD Nurse Specialist. We are blessed that Dr Murtagh and our other consultant, Dr Paul Minnis are still involved. Pat is an absolute angel; she gives the group so much valuable support, advice and time and we would be lost without her.

“We were delighted to be able to present a cheque for more than £11,000 to APF when Chair Steve Jones visited us. Our donation was, however, tinged with sadness as group member Alastair Magee (pictured with wife, Paula), passed away suddenly in December. He was only 52 and his death reminds us of how quickly this terrible disease can escalate.



“Here are some of our other achievements:

- In 2018 the group donated 300 hand-held rechargeable fans to patients at Antrim Area Hospital
- We have lobbied local politicians and gave a presentation at the council chambers asking for free use of recreational facilities for people with PF, a cause that we continue to fight for
- The group has developed information leaflets, providing tips and contact numbers for PF patients and their families
- We hold charity events as often as we can to raise funds for research. In 2019 we had a disco, coffee morning, raffles, lunch and a quiz night. We’ve also had runners in the Belfast and Melbourne marathons and two young men cycled the length of Ireland in 24hrs non-stop.

“There is now another group in Northern Ireland, at Altnagalvin Hospital in Derry/Londonderry and it is obvious from the number of calls and emails we receive asking for help, support, and signposting that more are needed. We are on the case! This year we will be meeting six times a year and speakers will include a clinical psychologist, physiotherapist, dietitian, respiratory consultant and our local benefits office. We’re also introducing a mentoring system for new members and their families, who will be buddied up at meetings to help them feel more comfortable.

“We’ve come a long way since 2016 but there is still a lot of work to do. We will continue to work with APF to find a cure and improve care for people with this terrible disease. We owe it to those PF warriors that are fighting this disease every day, for those who will follow and for those that are no longer with us.”

Support Group roundup



The **Sheffield Support Group** had a great response to the APF Listen to our Lungs campaign, held during Global PF Awareness Month. Group Chair Dr Stephen Bianchi persuaded the Rotherham and Derbyshire NHS Clinical Commissioning Groups (CCGs) to post messages on their intranets about the campaign and APF. This means that every GP practice in Derbyshire and Rotherham will be able to access information about spotting the sights and sounds of PF. Rotherham CCG also held a respiratory workshop for 130 GPs, trainees and nurses in January 2020 at which Dr Bianchi talked about the need for early diagnosis.

The Sheffield Group also staged their very own Bake Off (pictured above), judged by members of the Sheffield Hospital Charity, who provide essential support to the group. The Bake Off raised £220, with a cheque being presented to former APF Support Manager, Lorna McLauchlan. Thank you to Sheffield for all your hard work raising awareness and funds.

It was with great sadness that we heard of the passing of Ann Bennett of Falmouth late last year. Ann, who had IPF, had been a friend and supporter of Action for Pulmonary Fibrosis since the charity began in 2013, and was a member of both the **Exeter and Plymouth Support Groups**.

APF trustee, Howard Almond, recently visited Ann's husband, Peter and daughter, Heather, pictured right. "Ann was a witty, determined and inspiring woman and I was humbled to receive a cheque for £3,500 from the family."

The money was raised through donations in Ann's memory and by her granddaughter, Rosie, who ran the Cardiff half-marathon.

"Ann was a witty, determined and inspiring woman"



Bolton Support Group have been making connections with France! Jean-Michel Fourrier, General Secretary of APEFPI (the French IPF association) visited the group on a fact-finding mission. APEFPI are planning to launch regional patient support groups throughout France in 2020 and Jean-Michel was keen to talk to the group about how APF works in the UK. He spoke at length with Chair Steve Jones and visited the Lung Centre at Wythenshawe Hospital. Back in Bolton there was a brilliant presentation from Dr John Blaikley (Manchester University Research Fellow and Respiratory Consultant Physician) and Jean-Michel was able to meet a number of other senior clinicians.

Group organiser Steve Milward commented, "We were delighted that Jean-Michel chose Bolton PF Support Group out of all the Groups throughout the world to request our operational point of view." In addition, the Bolton group is in the process of applying for a Lottery funding grant of up to £10,000. Steve told us, "I attended a half day seminar on how to apply for a grant. The lady running it was very helpful and seemed keen to support small groups like ours." Watch this space!

When the **Princess of Wales Support Group** in Bridgend, Wales, decided to raise funds for APF during last September's Global PF Awareness Month they really hit the jackpot. The idea was to 'virtually' walk the circumference of Wales, adding up the miles via pedometers and smart phones. It was such a popular fundraiser that they not only completed their original challenge but carried on to 'walk' around the whole of the UK! The idea came from support group member, Keith Maws.

Readers may remember that we featured Keith and his wife, Marian, in our last issue when they talked to us about living with PF from both the patient and carer perspective. It is with great sadness that we have to report that Keith passed away late last year. We send our condolences to Marian and all at APF want to thank the group and the Maws family, who did so much to raise the magnificent amount of £5,345.



Group members Rob and Keith present the cheque to Debra, APF's new national support manager.

IPF Fighters captured on film

The **Sutton Coldfield Support Group** has launched a powerful new video – IPF Fighters – to raise awareness of pulmonary fibrosis. The group is run by the St Giles Hospice and University Hospitals Birmingham, and they launched the video during Global Pulmonary Fibrosis Awareness Month.

Jenni Fryer, a co-ordinator at the hospice, worked with the group to develop the video. "We wanted people to understand the impact of IPF on a daily basis, and show how this condition compared to cancer. But most importantly, the group wanted people to know that they are not alone, that there is help out there and that others will be there for you."

Monica Bett, one of the people featured in the film, said there was a real lack of awareness about PF amongst healthcare professionals and the public.

"When I first was diagnosed, I was given six months to live and offered no information or support. I left that appointment feeling absolutely lost and totally alone. I hope the film goes some way to making sure other people don't end up in the same situation."

IPF Fighters was filmed by Rob Price of T1 Media in Tamworth, who donated his time and expertise for free. "It's been an emotional process making the film and I am proud to have been part of it," he said. "I knew nothing about pulmonary fibrosis when I started working, but since then have learnt a huge amount, as well as hearing the stories of the fantastic people who are involved."

Sadly, Linda who features in the video died suddenly between filming and the launch. As Jenni told us, "This was a wonderful project to work on, but losing Linda shows the harsh reality of this disease, and makes us more determined than ever to raise awareness and funds to combat it."

You can see the video at www.stgileshospice.com/support-group-film-premiere-to-promote-awareness-of-pulmonary-fibrosis



Stan Andrews, who attends the Sutton Coldfield group with wife Maxine, is another IPF Fighter featured in the video

Living with PF – Keeping safe

Firefighter Ashley Fullard is a man on a mission. Since losing his beloved dad, Neil, to IPF a year ago, he is determined to help other pulmonary fibrosis patients stay safe in their own homes.

“My dad was diagnosed nine years before his death so he did well. But, as his condition worsened, I was constantly assessing him and the impact the illness could have on his safety. As PF is a progressive disease it is important to regularly re-evaluate your capabilities. Patients are so busy coping with the illness they don't think about the impact that decreasing mobility and using oxygen has on safety.”

Ashley, Watch Manager at West Bridgford fire station in Nottinghamshire, now wants to spread the word about safety to PF patients across the UK, in memory of his dad.



The Fullard family with dad, Neil

“My dad was a remarkable bloke. He worked hard and family was everything to him. He was a taxi driver and customers became friends. His PF was actually picked up when he went for his driver medical. He was a realist but he was positive. He'd say, 'I know I'm going to die but I'm not going to die today.' ”

Ashley and his sister Kerry even took three months leave to look after their dad, with mum Mary, so that he could stay at home as long as possible. He passed away in March 2019 and is much missed by his family, especially his four grandchildren, Georgia (8), Hugo (4), Arron (10) and Imogen (7).

Ashley has regularly visited support groups in the East Midlands and has either visited or arranged visits to over 30 patients to advise on safety.

Any individual or support group in the UK who would like a visit from their local Fire and Rescue Service can email him at ashley.fullard@notts-fire.gov.uk

Ashley's Top Tips for keeping safe:

- Oxygen increases fire risk. Keep these items at least 10ft away from oxygen: candles, open fires, electric razors, oil or petroleum-based products
- Keep oxygen cylinders secure and steady – Ashley made a box for his dad to have at the side of his chair or bed
- Some fire services record who uses oxygen in their area. Get yourself on the list
- Display a 'compressed gas' warning sign at home, maybe in your window. This will help the fire service if you have a fire. You can buy these at DIY stores
- If you've moved your bed downstairs is there a smoke alarm in the room? The fire service will do that free of charge. You are twice as likely to die in a fire without a smoke alarm
- How would you get out of the house if there was a fire? Make a clearway free of furniture and oxygen tubing. Plan an escape route and have a rehearsal in the dark
- Before bedtime, close inside doors, unplug electrical appliances (not the freezer or fridge!); put out candles and cigarettes properly; and keep door and window keys where you can find them.



"It is important to regularly re-evaluate your capabilities"

Caring for carers



The West Kent Support Group has a separate Carers Group which meets regularly and also has a WhatsApp group, which enables carers to keep in touch in between meetings. Pictured are Jenny, Anne, Dee and Jean at the January meeting.

There are around seven million people in the UK who provide unpaid care for others. If you are one of those carers you know that it can be tough, and the physical and emotional impact of caring for someone with a serious, life-limiting illness shouldn't be underestimated. We carried out a survey with patients and carers and they told us that they often feel isolated and lack the support and information they need:

"An information day specially for carers would be helpful and a special section on your website for carers, with practical advice and tips."

"A PF information pack for patients, carers and families would be useful, particularly for those who don't want to, or can't, attend a support group or who don't have access to online information."

"I would welcome the opportunity for my children to learn more about the disease – how it progresses, what the future holds etc. They are at work and can't attend appointments with us."

Here are some contacts that may help, and look out for more advice and information in future newsletters and on the APF website.

- You can find local PF support groups, which help carers and families as well as patients, at www.actionpulmonaryfibrosis.org/find-a-support-group
- APF also has a telephone helpline. Call us on 01223 785725 to speak to a specialist nurse or a patient ambassador
- The Carers Trust website at www.carers.org signposts to local services and Carers Centres
- Another useful website for carers is www.carersuk.org
- Your local hospice can also offer fantastic support. The hospice movement can be considered as a support at the end of life, but they are as much about living well with illness and disability. There are hospices in most towns and cities and they will all offer slightly different support. The Nottinghamshire Hospice is a good example of what you might also be able to find in your area. Have a look at their website www.nottshospice.org/our-care-services
- Or just Google 'support for carers in' and lots of support services will pop up.

All carers have the right to an assessment which looks at the impact their caring role is having on their wellbeing. This is carried out by your local council and aims to find out what might help make your life easier. Respite care may be offered to give you a break, or help with gardening and housework. www.carersuk.org has more details about assessments, or you can ask your GP for a referral. You can also apply for the Carers Allowance if you care for someone for over 35 hours a week. The NHS website has more useful information at www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers.

Lung transplants – a view from Andy and Alan

A lung transplant may seem like the holy grail for pulmonary fibrosis patients – the only real chance of having healthy lungs again. However, transplantation is complex and not to be taken lightly. Timing is key – it is not worth the risk if you are well and often too risky if you are poorly.

For every 10 patients who have a transplant, one or two will not survive the first year. In five years, only five will still be alive; after 10 years that drops to just one or two. Life after transplant can also be a challenge, demanding a strict drug regime and a healthy lifestyle. We asked Andy and Alan, who've had transplants, to give us an honest account of their experience.

If you have any questions, APF Chair, Steve Jones - who received a single lung transplant in 2016 - is happy to chat. Please call Emma on 01733 475642 to get in touch.



Andy Bright - in his own words

"In 2018 a stranger saved my life. He didn't pull me from a burning building or stop me stepping into the road – he donated his lungs. I still don't know who he was, but without him my wife would be a widow, my children fatherless and my grandchildren without their 'poppy'.

"In 2006 I was 42, working long hours running a business I loved. I played squash, badminton and golf every week, but one day late that year, I noticed that running up the steps at Villa Park I was out of breath. I thought 'You're getting old, mate'.

"The following year I developed a terrible cough that haunted me for the next 12 years. My breathlessness got worse – by 2012 my lung function was down to 45%. I had years of biopsies and scans, and eventually I was referred to Professor Gisli Jenkins at Nottingham in June 2013, who diagnosed pulmonary fibrosis.

"I was basically told that I would need a lung transplant within two or three years. Fast forward to August 2018 and my lung function is at 21%. I'm told to enjoy Christmas as it's likely to be my last. I wouldn't see my grandchildren grow up, I wouldn't walk my daughter down the aisle and I was pretty sure that I wouldn't see my beloved Aston Villa back in the Premier League.

"But on 18th September I received THE call! 'Hello, is that Andy?...Do you still want to go through with the transplant?' I was there in half an hour. The lungs went in and I was kept in a coma for eight days, but after six weeks in hospital, I was allowed home.

"Now, I'm looking forward to many more Christmases and I cherish every day. I'm working to get fitter, to prepare for the Transplant Games and I'm also planning to learn to dance so that after I've walked my daughter down the aisle, I can show her what a real dancer looks like!"



Alan and Jo with their two youngest children Alan and Ellie at the 2015 Transplant Games in Newcastle

Alan Wheeldon - six years on

Joiner Alan Wheeldon (53) had a young family and was about to get married when he was diagnosed with IPF in 2012. Two years later and just days from death, he gratefully received a double lung transplant at the Freeman Hospital in Newcastle.

"Towards the end I was on oxygen 24/7 and I'd lost five stone," says Alan. "I was basically sat in my chair waiting to die. When we got the call that they'd got lungs for me, I honestly didn't think I was strong enough to get through the operation. It has been hard over the past five years but, of course, I would make the same decision again."

Alan now takes 40 tablets a day and has steroid-induced diabetes and severe migraines. It is nothing compared to IPF but, says Alan, "You are swapping one big problem for lots of little ones." One of the unexpected issues is that he is struggling to find a job. "I am fit for work but you go for an interview and they see 'lung transplant' and don't give you a chance."

"Alan was in hospital for a month," recalls wife Jo. "I remember walking the hospital corridors and feeling so scared and lonely. Since the op we decided that we would live life to the full. We had a kind of bucket list and we've held tigers, swum with dolphins and driven fast cars! The first year was tough but now we have a really good life. What we will never forget is the 49-year-old woman who donated her lungs. We will forever be grateful to her and her family for this amazing gift."

Jo and Alan helped to set up the Hull and East Yorkshire PF Support Group and Jo hosts an online support group on Facebook at www.facebook.com/groups/1600842026822759. Alan takes part in the Transplant Games every year, and feels that every medal he wins is a thank you to his donor.

Meeting the criteria

The complexity of transplantation mean that there is a rigorous assessment process, which not all patients will get through. The criteria for eligibility varies between hospitals but to improve your chances of success you need to have good emotional and psychological support around you, and be:

- in good health with no other life-threatening illnesses like kidney failure, heart disease or cancer
- a non-smoker of at least six months and drink minimal alcohol
- happy to take medication as you will be on lots of tablets
- an ideal body weight
- under 65 - although people older than this who are otherwise healthy may be considered.

The NHS website has more information at www.nhs.uk/conditions/lung-transplant.

Health Tips – a good night’s sleep

Our Health Tips feature is always popular and when we asked what people would like to learn more about sleeping problems came high on the list.

Patients know that lung disease can make a good night’s sleep difficult. As we sleep breathing slows down and we do not take in as much air. Muscles relax, the upper airway narrows and the activity of muscles that control breathing is reduced. Symptoms such as coughing, breathlessness and heartburn may also keep you awake.

Advice from patients and carers

Brenda: “My husband is on oxygen and has to sleep with a cannula. It did drop out at night and was uncomfortable to wear. The hospital gave us a cannula with longer prongs to go into the nose and softer tubing. This really is more comfortable and hasn’t dropped out once yet.”

Katrina: “I have a small humidifier that I use during the night with lavender oil. I never have problems falling asleep but this seems to help me stay asleep.”

Bill: “My top tips are to get out and take a walk every day, don’t eat after 7pm, cut out alcohol and don’t watch the TV or go on your computer after 7pm.”

Howard: “I fall asleep easily but invariably wake up around 4am. Listening to the radio soon sends me off. I also find using a fan to keep the air moving helps a lot.”

Andy: “I was constantly tired and was tested for Obstructive Sleep Apnoea - common in people with lung disease, causing your breathing to stop and start during sleep. It was waking me up 14 times every hour! Some of that was down to IPF and some to putting on weight. I now use a Continuous Positive Airway Pressure machine which stops the airways collapsing. I’m also exercising more. My advice is watch your weight and talk to your GP if you think you could have OSA.”

Top tips for better sleep

As well as making sure your PF is being managed properly there are a number of things you can do to improve your sleep.

- Keep to a regular sleep schedule. A daytime nap is fine but avoid long naps as this can affect your sleep at night
- Avoid caffeine and alcohol at least six hours before bed. A light evening meal is also recommended
- A hot bath 90 minutes before bed, or soaking your feet in hot water, can help you fall asleep
- A quiet, clean and tidy bedroom encourages relaxation. Keep noise out and the temperature to around 20 degrees
- Reduce ‘blue screen’ time two hours before bed - TV, tablets, phones and computer screens reduce melatonin, the sleep hormone
- Take some gentle exercise, preferably around mid-morning. Exercise too late at night disrupts sleep
- Try to get plenty of exposure to daylight. It’s important for the circadian rhythm, improving daytime wakefulness and night-time sleep
- Use a pillow or wedge to help keep you on your side as this opens up the airways. Make sure your head is in an upright position and not lying flat.



Big cats sleep up to 20 hours a day – even in seemingly uncomfortable places!

Go along to your local PF Support Group to share your experiences, and visit the APF website or www.sleepcouncil.org.uk for more information.

The joy of cycling – with support!

E-bikes – electric-assisted bicycles – can offer a fantastic opportunity for exercise for those living with pulmonary fibrosis.

Cycling was everything to Tim Gregory when he was diagnosed with PF 10 years ago. He had to give up cycling and started suffering from depression. But when a friend suggested he tried an e-bike, the now 51-year-old admits it completely changed his life. Tim, pictured right, even switched careers and founded Smilebikes to help others like him.

“With the illness and giving up cycling, my life came tumbling down. To be able to ride with my friends again meant the world to me - it felt like I had been given a second chance.”

APF Chair Steve Jones is also an advocate of e-bikes.

“E-bikes are great because your lungs still have to work, but faced with a hill you get extra support. I bought my first electric bike back in 2014 - a heavy Chinese bike with a powerful battery. After my transplant in 2016, I looked for a lighter e-bike and found a company specialising in electrifying standard bikes. Mine weighs only 14kg, so I can lift it onto my car's bike rack. I now go cycling every Thursday with some mates - having an e-bike means I can keep up and enjoy the ride.”

E-bikes aren't cheap but they hold their price reasonably well. Just Google e-bikes to find suppliers near you or visit www.smilebikes.co.uk



Making a Difference – Dr Diane Laws

In a new feature looking at people who are making a difference to the PF community, we spoke to Dr Diane Laws, Respiratory Consultant at the Royal Bournemouth Hospital.

Diane has worked as a consultant for 18 years and was increasingly concerned that patients with PF waited a long time to be referred and get treatment. She decided to see how things could be improved.

She attended conferences and read up on PF. She then set up a clinic in Bournemouth to offer more rigorous diagnosis for fibrosis and develop closer links with the specialist service in Southampton. A specialist nurse has also been trained up and patient leaflets produced.

This link between Bournemouth and the Southampton specialists and the increase in awareness of PF, mean that patients are diagnosed more accurately, are referred sooner for treatment, and that investigations and ongoing treatment can be done locally.

“My ambition is to see more arrangements where local clinics link with specialist centres, to speed up diagnosis and treatment and raise awareness amongst health professionals. I also believe that ILD should get the same resource as cancers, for instance through specialist nurses.”

Diane describes her greatest achievement as the positive feedback she gets from patients. APF's thanks go to Diane for making a real difference to her patients. If you'd like to nominate someone, whether family, friend or health professional, contact the editor at debbie@djprm.co.uk and we'll try to feature them in a future issue.



Research News

Action for Pulmonary Fibrosis is one of the leading funders of PF research in the UK and is committed to finding a cure for the disease. Thanks to the efforts of our exceptional fundraisers, we have been able to fund two Mike Bray IPF Research Fellowships, totalling £580,000.

As well as directly funding projects, we also advise on other studies to ensure that the patient voice is heard. We are currently involved in two projects funded by the National Institute of Health Research (NIHR). APF's active engagement has led to improvements in study design, including reducing the number of patient visits to hospital and more patient-friendly survey forms. Our involvement on project steering committees has also smoothed implementation. Later, our task will be to ensure research findings are communicated in a way that the general public can understand.

The Mike Bray Research Fellowships

Dr Richard Allen of Leicester University is investigating the genetic causes of IPF. This project will compare the DNA of people with IPF to identify genes that explain why some experience severe disease and others have milder symptoms.

Dr Philip Molyneaux, of Imperial College London is looking at the impact of lung bacteria on the disease and the potential use of antibiotics.



The INJUSTIS team

The INJUSTIS Study (It's not JUST idiopathic pulmonary fibrosis study)

This study – as its name implies – is not just about IPF, which has no known cause. It aims to identify characteristics – biomarkers – which are common to all types of progressive fibrotic lung disease in pulmonary fibrosis. These include IPF, chronic hypersensitivity pneumonitis (HP), asbestosis, rheumatoid arthritis-associated interstitial lung disease (RA-ILD) and unclassifiable pulmonary fibrosis.

The study is being led by APF Trustee, Professor Gisli Jenkins of Nottingham University Hospitals at 25 UK hospitals. Two hundred patients with fibrotic lung disease are taking part. They will give blood samples, have lung function tests and complete quality of life questionnaires

and some will be offered a bronchoscopy. The aim is to identify a biomarker that predicts how the disease will progress and, in turn, develop new treatments that will target the mechanisms that cause scarring.

The TIPAL Study (Treating IPF with the addition of lansoprazole)

It is well known that people with PF often have reflux disease which can cause acid from the stomach to be breathed into the lungs and damage them. This study aims to see if taking daily lansoprazole, a drug used to stop the stomach producing acid, slows the rate of lung function decline in PF patients.

The study will be led by Professor Andrew Wilson of the University of East Anglia and will involve patients from over 30 hospitals. As well as looking at the potential rate of lung function decline, researchers will also see if lansoprazole impacts on cough and quality of life. If lansoprazole is shown to slow progression, it could be recommended for widespread use for PF patients.

As part of TIPAL, APF will be leading a small sub-project to see if we can improve recruitment and retention of patients in clinical trials of this kind by involving the PF support groups.



Patients set to join APF at Warsaw summit in April

Patients Driving Change - the first ever Europe-wide IPF and PF patient summit - is being held in April in Warsaw, Poland and APF is ensuring that the voice of UK patients will be heard.

The charity has provided grants for patients to attend and although applications for a grant have now closed, if you are able to self-fund the trip you may still be able to attend.

The EU-IPFF Patient Summit will be held on April 24-26 2020 and will bring together hundreds of patient groups, healthcare professionals and policy makers from across Europe to share ideas and learn from each other.

You may still be able to book a place at www.euipffsummit.org - or contact APF's National Support Manager, Debra Chand, for more information on 01733 475642 or info@actionpulmonaryfibrosis.org.



Look out for a full report in a future newsletter!

Learning from America



Steve and Louise with Bill Vick, founder of PF Warriors, a voluntary organisation of patients and carers with members in 48 US states and 13 countries.

Action for Pulmonary Fibrosis representatives joined delegates from 10 countries and 40 states at the third US Pulmonary Fibrosis Foundation conference in Texas. Chair Steve Jones and Chief Executive Louise Wright were there to learn from patients and health professionals in the US and bring that knowledge back to the UK. Louise gives her reflections.

“Listening to patients talk about their diagnosis of PF is not your average start to a conference, but it was a welcome one. Patients were also integral to panel discussions, bringing their experiences into what can be very medical discussions.

“Talking with patients, most of whom had had lung transplants, I was grateful for our often-maligned NHS.

Many families were pushed to breaking point to cover costs their medical insurance refused to pay. Oxygen therapy causes a great deal of anxiety, being difficult to get and pay for.

“The key things I learned were:

- Pulmonary fibrosis knows no boundaries. The shock diagnosis, the bewilderment and emotional impact on families is all too familiar wherever you are from.
- Collaboration is key. PF has a far reaching impact on families, on health and social care systems, on employment... the list goes on. Working with others is the only way we can help families now, and find a cure for the future.
- Both the Pulmonary Fibrosis Foundation and APF are experiencing a battle to increase awareness of the disease in their respective countries.
- The number of clinical trials that should bring new treatments over the next five years has grown, with treatments also looking at reflux and cough, not just the disease. PF is attracting interest from some of the best researchers in the world.

“Many patients were interested in visiting UK support groups. If you would like to visit a US support group or encouraging your US counterparts to say hi, please email Debra at debra@actionpulmonaryfibrosis.org and we'll help this mutual learning continue.”

Thank you to the Pulmonary Fibrosis Foundation for making APF so welcome. You can visit their website at www.pulmonaryfibrosis.org or find talks from the summit on YouTube.

Our fundraising stars

We are constantly amazed and humbled at the passion and effort our fundraisers put into raising much-needed funds to support APF's work. Their commitment helps families affected by all forms of pulmonary fibrosis here and now and funds research to find a cure. But we are very ambitious.

We want every patient and their family to have the support and care they need and deserve. Over the coming years we want to develop our services so that we can reach everyone affected by PF. We also want to fund more research to speed up the search for a cure. Your continued fundraising gives families hope. Thank you.

Here we showcase some wonderful fundraisers – why not join them and be part of the growing community that is saying NO to pulmonary fibrosis.

Joe's 5k-a-Day Challenge

Joe Reid, a 19-year-old student from Aberdeen, lost his dad to IPF in September, 2018. In his memory Joe set himself a challenge to run 5k every day in September, 2019. Joe, pictured right, admitted to being very unhealthy, a fussy eater and extremely inactive, but despite these supposed drawbacks he completed his 150k task – with some help from his enviable location! "I'm extremely lucky to have Aberdeen beach at my doorstep which is great for running – until it gets windy!" said Joe, who raised £3,700, featured in his local paper and raised awareness of the disease. Well done, Joe.



Fellowship researchers AND fundraising runners

As you may know, APF awarded two Mike Bray Research Fellowships to Dr Richard Allen and Dr Phillip Molyneaux last year. As well as working in IPF research, Richard and his girlfriend Olivia (left) have recently run the Chesterfield Half Marathon to raise funds for the charity. Inspired by their success, Phillip will now be joining the team of runners taking part in the London Landmarks Half Marathon next year. Thank you both for your commitment!

Wilf's Christmas Cards

APF offered a range of Christmas cards thanks to the support of fundraiser Camilla Inglis and her son Wilf. Camilla explained, "My wonderful friend died from Pulmonary Fibrosis in November, 2017. Wilf, my eldest, talked with her family about robins and their connection to lost friends and he painted an image of the bird. My friend wanted APF to benefit after her death and so the Christmas card idea was born." The robin featured on the cards alongside Wilf's wintry owl. In addition, APF newsletter designer Tim Stone contributed a traditional holly photograph, and all proceeds were donated to APF.

Cheers to Cheltenham and Gloucester

Our thanks to Stan and Margaret Fryatt, pictured right, from the Gloucester PF Support Group, for supporting APF throughout the past year. Margaret is chair of the Cheltenham 8 o'clock Club which named APF as the group's Charity of the Year. They raised a fantastic £1,644 and Carole, one of the members who attends another social club in Gloucester, added another £740.



Huge sum raised by George Vet Group

Veterinary staff who set out to raise £3,000 for APF handed over a cheque to Chair Steve Jones for an incredible £47,290 following a charity cycle event held in September.

APF became close to the George Vet Group's hearts when director and much-loved colleague Tim Hirst passed away in July from pulmonary fibrosis, at the age of just 39. "He had been right behind plans to raise as much money as possible with an inaugural cycle ride to support APF. With Tim in our minds and hearts we wanted to do our very best in his memory," said the Group's Marketing Manager Jason Vernon.



What started as a fairly modest event, with 12 riders from Gloucestershire and Wiltshire, took on a whole new meaning. On the day 241 riders completed either the 35km or 100km course, with hundreds more looking after rest stations, baking cakes, shaking buckets or just cheering everyone along.

This was a fitting tribute to a man who meant so much to so many people. APF is delighted to continue the relationship with the Group by welcoming two of the vets to the London Landmarks Half Marathon team.

Remembering mum

"Our mum was the most inspirational woman and best role model we could have wished for." So say Malini and Nishel, who lost their mum, Pushpa Patel, in June 2019, following her diagnosis of IPF. They decided to take on the Kew Gardens 10k to raise money for their local hospice and APF in her memory. "We wanted to raise money for these amazing charities so that they can continue to support people through their toughest times and to help fund much needed research."

The sisters, pictured right, smashed their initial £500 target to raise £1,350.



Get involved

Climbing high or sky diving, biking or hiking, baking a cake or swimming a lake – there are endless ways you can raise funds and awareness. For help and support contact Sharon Moon, Fundraising Support Co-ordinator, by emailing fundraising@actionpulmonaryfibrosis.org.

You can also take it easy and donate to APF while you shop online. Amazon Smile (smile.amazon.co.uk) lets customers enjoy the same shopping features as Amazon but will allow you to donate 0.5% of the net purchase price (ex VAT and shipping fees) of eligible purchases to your chosen charitable organisation. Have a look next time you're shopping at Amazon. Similarly Give as you Live (www.giveasyoulive.com) is linked to over 4,400 leading stores so when you shop online at their website you can support APF too!

Making an impact at BTS

The British Thoracic Society (BTS) is the leading UK membership organisation for healthcare professionals interested in better lung health for all. They hold two extremely well attended conferences every year, and APF joined their latest conference in London in December 2019.

It provided a great opportunity to increase awareness of support groups amongst doctors and nurses, increase referrals to our support line service, and use the patient voice to improve healthcare and research practice across the UK.

This year's APF speaker was Dr Joyce Lee of the University of Colorado, who gave an excellent presentation about PF associated with rheumatoid arthritis (known as RA-ILD). An estimated 10% of RA patients develop the condition, which can progress as rapidly as IPF. Steve Jones, APF's Chair, spoke to health care professionals with a special interest in pulmonary fibrosis about the charity, encouraging them to refer patients to us.



And we were extremely pleased that Dr Richard Allen, our APF Fellow, won the New Investigator Award for his research to date on genetics linked to IPF, pictured above.

APF Support Line is there for you

"Thank you APF. You gave the gift of time to listen to me."

As the APF Support Line enters its third year it's going from strength to strength. It operates as a free 'call back' service. You call us on 01223 785725 and leave a message, night or day, and get a call back within two working days. Or you can email us at supportline@actionpulmonaryfibrosis.org.

The Support Line has helped hundreds of people with questions about everything from anti-fibrotic drugs and oxygen to exercise and travelling abroad. Specialist nurse Lucy Rodrigues answers most of the calls, with support from APF trustees. And, while most of our callers are patients, a significant number are carers. Here are a few of the comments we've received:

"I never thought of myself as someone that would call a support line. I'd reached a point where I needed information and sound advice. I got so much more. I found positivity and hope. I can't underestimate the value of that."

"I have spoken to Lucy several times about my Grandad who has IPF. Every single time she's been knowledgeable and gone into great detail with any questions I have had."

Contact Us

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

www.actionpulmonaryfibrosis.org
facebook.com/actionpulmonaryfibrosis
twitter.com/actionpfcharity

Email: info@actionpulmonaryfibrosis.org

Support Line: 01223 785 725

Newsletter: If you have a story to share or feedback on this issue, email debbie@djprm.co.uk or call 07498 056979



This newsletter has been produced with the support of Boehringer Ingelheim



Copyright © 2018 Action for Pulmonary Fibrosis
Registered charity 1152399 (England and Wales)

Action for Pulmonary Fibrosis, CO/EBS, City Wharf, Davidson Road, Lichfield, Staffordshire WS14 9DZ