

## APF Patient Survey exposes unacceptable misdiagnosis

A huge thank you to the 776 people who responded to our IPF Patient Survey last summer. We have analysed the results and our findings and recommendations are being shared with the NHS, Department of Health and Social Care and Government.

This large-scale survey by APF of people with idiopathic pulmonary fibrosis has uncovered a widespread and unacceptable level of misdiagnosis. The survey revealed that 35% of respondents were misdiagnosed while only 46% said they had been correctly diagnosed within six months of visiting their GP. This is denying patients with a severely life-limiting disease early access to the care they need to manage their symptoms, improve their quality of life and even extend it.

Steve Jones, Chair of APF said: "While we recognise that pulmonary fibrosis is difficult to diagnose and NHS staff are doing their best, we believe it is unacceptable that so many people are misdiagnosed. Some have to wait not just months but years for an accurate diagnosis. Action for Pulmonary Fibrosis is calling on NHS England to prioritise improvement in the rate of diagnosis for this condition. We're encouraged by the recent announcements in the NHS Long Term Plan but also want to see renewed commitments to specialist nurses as part of the upcoming workforce implementation plan."

See more of our findings on page 3.

## Katie and Steve talk lung transplants

APF Chair Steve Jones has been talking about lung transplants with Katie Price and her mum Amy, who was diagnosed with pulmonary fibrosis two years ago.

You may have seen Katie and Amy on the Loose Women chat show back in April, when they talked about her diagnosis and the possibility of a lung transplant. They also raise the issue on Katie's My Crazy Life reality TV programme, after meeting Steve to share his experiences of having a transplant.

"Lung transplantation is not a cure for PF and carries its own risks. I lived with PF for eight years and, as my condition was deteriorating, my consultant suggested a transplant assessment. This is a rigorous process which examines you both medically and psychologically. You need to have the right mind set and support system to deal with the risks and the consequences of having a transplant.

"I also had a cardiac assessment to make sure I had a good chance of getting through the operation. In the end, I was offered a transplant within 12 days of going on the list. That was in spring 2016, when I was 67 years of age. I've been very lucky and have been on good form ever since."

**"Lung transplantation is not a cure for PF and carries its own risks."**



Steve met Katie and Amy at a House of Commons campaign meeting a couple of years ago and invited Amy and husband to the Papworth Support Group. Amy was keen to talk about transplants, and this year asked Steve to get involved in Katie's TV programme.

"I met Amy and Katie in a café in London and our conversation was filmed. They were both great to talk to and I admire the fact that Katie is using her celebrity to support good causes."

You can see My Crazy Life at [www.questod.co.uk](http://www.questod.co.uk) for a limited time, and read more about lung transplantation on the APF website: [www.actionpulmonaryfibrosis.org/about-pulmonary-fibrosis/lung-transplantation](http://www.actionpulmonaryfibrosis.org/about-pulmonary-fibrosis/lung-transplantation)



## Welcome

Welcome to the Summer 2019 edition of the Action for Pulmonary Fibrosis newsletter.

Support groups continue to grow and there are currently over 70 groups on our website, with plans for new launches including those in Denbighshire, Brighton and Chester over the next few months.

Action for Pulmonary Fibrosis has continued to reach out and visit established groups around the UK and I would like to take this opportunity to thank groups and their members for the very warm welcome we always receive at these visits.

I had the privilege to travel to Northern Ireland in April to meet with the Antrim Pulmonary Fibrosis Support Group. I am always overwhelmed when visiting groups by their generosity and kindness.

It is also wonderful to see groups supporting one another and many groups providing support to carers. Support groups remain a central focus for the charity and APF cannot thank you enough for the work you all do in raising funds and awareness of PF.

Please continue to send us your updates for the newsletter.

**Lorna McLauchlan**  
National Support Group  
Co-ordinator

## Chair's report from Steve Jones

Since APF was set up six years ago, we have grown rapidly and are now the largest charity in Europe focused on supporting patients and their families living with pulmonary fibrosis (PF).

We facilitate a network of 70 support groups across the UK, run a telephone support line and educate GPs and nurses in diagnosing and treating PF. We also lobby for improved care under the NHS and fund research to find a cure for the disease.



Following publication of our 2018 patient survey, we have achieved amazing coverage in the national media including the Daily Mail, Daily Express and Daily Mirror, in regional papers and on TV. We hope this will lead to a surge of media interest in covering problems facing people living with the disease.

Also this year, we launched two major three-year research projects (on the genetics of IPF at Leicester University and the role of bacteria in disease progression at Imperial College London), which should lead to new treatments in future. We are also contributing to other major university research projects on gastric reflux and biomarkers, which could lead to personalised treatments for patients.

We are now entering an exciting expansion phase, led by our new Chief Executive, Louise Wright. This should see us bringing benefits to more and more patients and generating increasing funds for research to find a cure for the disease. All this has been made possible by our amazing supporters. We are proud to be a patient-driven organisation so, if you think we could do better, please let us know!

## Working together to raise awareness

At APF we understand many patients are keen to improve awareness of pulmonary fibrosis by GPs and other medical professionals to speed up diagnosis. We've collaborated with pharmaceutical company Boehringer Ingelheim, helping them to understand what it's like to be a patient. They have started a number of initiatives to raise awareness of PF with medical professionals.

Boehringer Ingelheim have developed training for GPs that covers what to look and listen out for when patients have PF, what tests to carry out before a referral, where to refer patients, what further tests can be done, and finally what treatment options there are.

They have also developed an online campaign that is available on healthcare professionals websites to raise awareness of symptoms, why early diagnosis is important, what the medical professional can do and how to support the patient. This training is proving to be popular amongst healthcare professionals.

Working with a specialist centre they have developed a video aimed at patients visiting the centre for the first time. By providing practical information that ranges from where to park, who you'll see, to the tests you'll undergo, it aims to reduce the anxiety many patients feel.

Louise Wright Chief Executive at APF says, "It's clear that we have the same aims at the heart of our work, to improve the lives of patients and their families. We can see they use their resources to bring a broad range of benefits to patients. Thank you to Boehringer Ingelheim for supporting the growth of our support groups and sponsoring this newsletter."

## Patient Survey exposes unacceptable misdiagnosis

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The APF survey captured the views of IPF patients on the care they receive, and compared these to the national standards set by NICE (National Institute for Health and Care Excellence). It exposed some remarkable findings:

- 35% of respondents report being misdiagnosed, most commonly by GPs but also by hospitals
- 54% of IPF patients had wait more than six months to be diagnosed, with 20% taking more than two years
- 29% of patients lack access to a specialist nurse who understands about IPF care and treatment
- Only 53% of IPF patients have completed a pulmonary rehabilitation course of exercise and education
- The number of patients feeling well supported has dropped from 76% in 2015 to only 63%

### The recommendations

1. Create a clear patient pathway to ensure timely, accurate and confident diagnosis and treatment of all people with pulmonary fibrosis.
2. Increase access to ILD specialist nurses.
3. Improve IPF patients' access to pulmonary rehabilitation courses, specifically those run for pulmonary fibrosis patients.
4. Increase the number and effectiveness of pulmonary fibrosis support groups and provide better support to more isolated patients.
5. Encourage research and development into new technologies to speed up diagnosis, support effective treatment and give early warning of acute exacerbations.

A successful strategy will see the NICE Quality Standard implemented for every patient with IPF in England. We look forward to discussing how these plans can be ensured while working with the NHS in Scotland, Wales and Northern Ireland to achieve the same in all parts of the UK. However, while national level policy changes are critical for long-term outcomes in IPF, the recommendations above can be acted on now, which we believe will have an immediate impact on IPF patients.

APF has already had a positive response from the Royal College of General Practitioners who have asked how they can work with the charity to improve diagnosis. An e-learning module for GPs is being developed, with APF providing expert input.

Steve Jones commented, "This is a very encouraging early step and shows just how important the responses to our survey were."

### The reality behind the survey report

Charlotte Harvey is one of the many people who were initially misdiagnosed when she started having breathing problems three years ago. Her mother Anita had died the year before from idiopathic pulmonary fibrosis. Charlotte naturally feared she had the same condition, but her doctors told her she was too young and that it was just stress.

Charlotte was misdiagnosed with bronchiectasis – generally a less serious condition which makes the lungs vulnerable to infection. She eventually persuaded her GP to send her for a CT scan, and was finally told she had IPF last April.

"I was very, very angry. They even said it was not hereditary. I was fobbed off for two years. Most people live for no more than a few years and I had wasted two, battling to get diagnosed," said Charlotte.

She gave up her career as an operations manager, setting up a gift shop. Charlotte also raises awareness of IPF and supports others with the condition.



Charlotte Harvey

## Support Group round-up

This summer sees APF supporting over 70 groups. Here's some of their news from around the UK – starting with Northern Ireland.

The **Antrim Area Support Group** has been running for three years now and established links with APF this year. Support Group Co-ordinator Lorna McLauchlan travelled to Antrim to meet the group and talk about the charity. “Chairman Tom McMillan is working hard to raise awareness of the condition in the area and has asked for our support in setting up two new groups in Enniskillen and Down Patrick. I had a very warm welcome in Antrim and was well looked after by Tom and his wife Una.”

Antrim was one of the groups across the UK infected by the singing bug recently with coaches attending meetings to see how singing can help with respiratory problems. Antrim members sang along with Karen Diamond, who runs a Singing for Lung Health choir with all members having a chronic lung condition, at their April meeting. She soon had everyone singing their heads off and gave great advice on breathing exercises.

The **Swansea Support Group** started singing sessions last year with Carol Shepherd. Gentle, seated breathing exercises are followed by singing and even an attempt at some harmonies in a Ghanaian chant! A session was also held at the **Plymouth Support Group** earlier this year with coach Sandra Smith leading the way.

The **Nottingham Support Group** tried singing last year and loved it so much they had their second session in May with oxygen nurse, Linnie Bush. Among the song requests were Sisters by The Andrews Sisters...and if you remember them you are getting old!

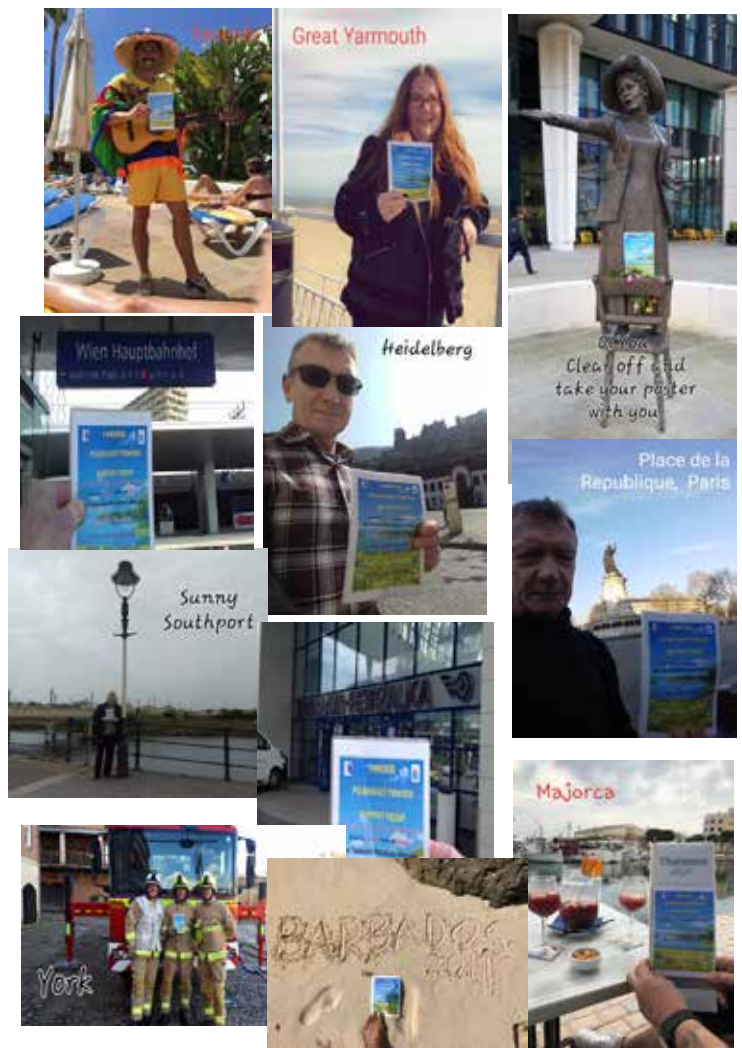
The **Tameside Support Group** were joined by singing coach Caroline Ratcliff in May. Founding member Sue Green said, “We thought that she might find herself singing alone because of trepidation about singing in front of others, but thankfully we were wrong. We certainly weren't the Kingdom Choir and will probably never sing at a Royal Wedding, but we gave it our all and had great fun in the process!”

**Tameside** have also been spreading their wings around the world, with the aid of a poster and some nifty camera work! The group has been encouraging people who are off on holiday to take a colourful poster about pulmonary fibrosis with them and take a photo with it to share with everyone back home. Photos are posted on Facebook and Twitter and lots of people are being asked about PF in airports and resorts. The poster has been as far afield as Dubai, America, Bratislava, Tunisia, Syria...and many more as you can see from the pictures on the right. Still on the wish list is the International Space Station!

In April, the award winning Silver Spectrum Wind Band held a fund raising concert for the **Sheffield Support Group** at St Timothy's Church in Crookes. Musical Director Michael Cox led the band through a varied programme of music, from a compilation of theme tunes by Henry Mancini to Verdi's March from Aida. The concert raised more than £200 and was thoroughly enjoyed and appreciated by all who attended. Special thanks to members Peter and Christine Newton and their daughter, Lauren, who plays clarinet and flute with the Band.

Another focus for support groups recently has been the needs of carers. The **West Kent Support Group** asked carers if they would like a separate group, and they jumped at the chance. The meetings provide a safe place to air their feelings, worries, concerns and has been helpful in letting them know they are not alone. There is also a WhatsApp group, which enables carers to keep in touch in between meetings.

### Around the World with TPFSG



The **Wessex WILD Group** includes carers in their group meetings so that they are as equally informed as patients. They have their own separate breakout sessions within meetings, where they may discuss carer specific concerns and interests and ask any questions they may have.

**Sutton Support Group** welcomed four supporters of a different kind to their May meeting - Judith and her three therapy dogs Keira, Harvey and Byron. Exceptionally well behaved, they instantly brought a sense of peace to the Group. Those of us with our own dogs quickly took great pleasure in fondling ears and tickling chests. However, even those who were nervous soon came under the spell of the three rough collies before the end of the meeting.



## Managing treatment side effects

There are two drug therapies available to some people with idiopathic pulmonary fibrosis (IPF). The National Institute for Health and Care Excellence (NICE) provides guidance on who is most suitable to receive Pirfenidone or Nintedanib in England. Both medications help to slow the scarring rate within the lungs. Whilst not a cure, research shows that they may reduce the rate of decline in lung function by about 50%.

The evidence base is similar, so information on both drugs is provided to patients so that they can make an informed choice. As with many drugs, both may cause side effects. ILD Lead Nurse Emma Harris from Royal Papworth Hospital explains the risks and how to manage them.

“Both drugs may cause changes to liver enzymes, so liver function tests are monitored regularly, particularly in the early stages of treatment. They can cause nausea, but this often only lasts a few weeks and can be helped by a reduced dose, lighter meals, anti-sickness medication and taking the drugs with food.

“A potential side effect of Pirfenidone is photosensitivity. Patients are advised to apply factor 50 UVB sunblock daily, even in winter, and to avoid prolonged sun exposure. A mild reaction may just need a reduction in the dose or can be treated with steroid based cream. If the reaction is more severe, treatment is stopped and then slowly re-introduced as appropriate.

“Heartburn or indigestion can be managed by switching to small light meals, avoiding eating late in the evening and taking anti-reflux medication. Weight loss and reduced appetite may also affect some people, so weight is monitored and a referral to a dietician made if necessary. Side effects of Pirfenidone are often more common at the start of treatment and improve over time.

**“This might all seem a little daunting, but many side effects are manageable so talk to your ILD team for advice.”**



“Nintedanib can cause diarrhoea or tummy upsets. Loperamide tablets can be taken as needed and you should avoid high fibre, spicy or greasy food, or large amounts of dairy. The dose may be reduced or treatment stopped if effects are severe. Nintedanib carries a slightly increased risk of bleeding, so seek advice from your ILD department if you take drugs such as Warfarin or Clopidogrel or have surgery planned. This might all seem a little daunting, but many side effects are manageable so talk to your ILD team for advice.”

Action for Pulmonary Fibrosis has produced detailed leaflets on both drugs. You can find them on our website at [www.actionpulmonaryfibrosi.org/for-healthcare-professionals](http://www.actionpulmonaryfibrosi.org/for-healthcare-professionals). You can find out about the NICE guidelines at [www.nice.org.uk](http://www.nice.org.uk)

## Spotlight On...

### Northamptonshire Pulmonary Fibrosis Support Group

Penny Tremayne dreamed of starting a support group for people affected by pulmonary fibrosis in Northamptonshire following her mother's death from the disease. It took 18 long months to launch the group earlier this year. On the day, the normally confident Penny was convinced that no-one would turn up! She needn't have worried – more than 30 people crammed into the (by now too small) room and she finally relaxed. APF's Ambassador Wendy Dickinson was privileged to speak at the meeting. We asked Penny if she would share with us some thoughts about her mum, and starting the group.

"Let me tell you about my mum. She was beautiful, intelligent, spirited and adventurous. A quick-witted Scot, she did not suffer fools gladly. She travelled the world and was a nurse and midwife.

"She was inspiring in all that she did, however her life and vitality weakened when she received the diagnosis of IPF. I recall clearly the day we got the diagnosis. We were both relieved it wasn't cancer but in retrospect maybe we would have got more support if it had been. Instead we got very little help and we floundered. This group is in part for her, in part for me but ultimately for others, as they deserve better.



Brenda and Penny

"Steve Jones, Chair of APF, advised that I contact Brenda Coe who, alongside her late husband Mick, started the Leicestershire Group. We discovered we lived near each other and so we could meet up easily. I don't think the Northamptonshire Group would be where it is now without Brenda's support. Things really got moving when Lorna McLauchlan, APF's Support Group Co-ordinator, got involved and proved a constant source of encouragement. In addition, Charlotte Harvey, who has PF, has been very proactive and inspiring in promoting the group and anything to do with the condition.



Forging links with clinical practice has also been important. The Restart team based at Northampton General Hospital NHS Trust have been brilliant, as has Leicester Interstitial Lung Disease Service at Glenfield Hospital."

### Lessons learned and a look to the future

- Keep to a regular date, time and venue for meetings. The nature of PF means early afternoon is best and a central venue that is flat, spacious, well ventilated and has facilities for a drink is best
- Identify a treasurer once the group is established
- Plan the year ahead with a mix of speakers and informal get-togethers
- Generate regular income by having a raffle to pay for room hire.

**"I am determined to do what I can to make a difference to people affected by pulmonary fibrosis."**



"Most important for us is to raise awareness of the group and of pulmonary fibrosis through the media and communication with local clinicians. We are also considering campaigning and fundraising initiatives. It has been a privilege and a pleasure to create this group for such fantastic people. It remains a voyage of discovery and the range of emotions I've felt has surprised me. I've gone from anger and frustration to upset at the loss of a group member. I really care for the group so much, for the individuals in the group and the purpose it serves...just everything about it. I am determined to do what I can to make a difference to people affected by pulmonary fibrosis."

Meeting information and contact details for the group can be found here...  
[www.actionpulmonaryfibrosis.org/find-a-support-group](http://www.actionpulmonaryfibrosis.org/find-a-support-group)

## Living with Pulmonary Fibrosis *How palliative care can help*

Research Scientist Clare Beckett was diagnosed with IPF at the relatively young age of 37. Here she shares her experiences of palliative care, which is often misunderstood. Palliative care may be confused with end-of-life care, but it is much more. It focuses on providing relief from the symptoms and stresses of living with a serious illness. Its goal is to improve quality of life for the patient and their family throughout their journey.



“On a snowy January morning, feeling a mixture of anticipation and trepidation, I walked through the doors of my local hospice. At my request I had been referred as an outpatient, with the opportunity to take part in a HOPE programme. This involved meeting with a small group of people with life-limiting conditions for two hours a week for six weeks.

“Led by two wonderful occupational therapists, I spent quality time each week with five amazing individuals talking about our concerns and anxieties. We learned coping strategies for managing our emotional and physical well-being and explored practical tips for dealing with setbacks, fatigue and sleeping problems. We also ate a lot of delicious cake and drank copious amounts of tea!

“It was a very positive experience. I finished the course feeling less alone, better informed about the help available, and energised by taking some time for myself. Spending time at the hospice has helped me understand that they offer supportive care for your entire journey, not just the final moments.

“My local hospice is full of light and colour, a welcoming and tranquil place. There is a strong sense of community and camaraderie, and it feels like a safe space to express whatever you need to. Support is available from the day of diagnosis, including counselling, legal advice, physiotherapy, complimentary therapy, social activities, and short-courses like HOPE.

“They also provide support during symptom exacerbation with short-term inpatient or home care, which has been very reassuring for me. Both my mum and aunt battled with PF and had very different experiences at the end. I am clear what I would choose, but now I know how I might achieve it. Furthermore, a huge comfort comes from knowing that carers and immediate family can also access their services at any time.

“For now, I am continuing with day therapy once a month and am looking forward to some self-care with my first session of reflexology. I would encourage everyone to engage with a local hospice, at whatever stage of illness, if only to find out what support is available along the way.”

### A special partnership

APF recognises that we need to work with other organisations – clinicians, specialist nurses, NHS commissioners, drug companies and other charities – in order to maximise benefits for people living with pulmonary fibrosis (PF). A key partnership for us is with the Interstitial Lung Disease Interdisciplinary Network (ILD/INN), an organisation of specialist nurses and other health care professionals.

Specialist nurses are fundamental to good quality care for PF patients. As the NICE Quality Standard recognises, they are uniquely placed to ensure that patients, families and carers receive the information they require. Specialist nurses support patients to ensure they have timely access to the care they need and are trained to discuss sensitively prognosis, disease progression and life expectancy. APF has so much to learn from specialist nurses and health care professionals but there is also a lot we can achieve by working together.

APF supported the establishment of ILD/INN in 2015 and is proud to be one of the leading sponsors of their annual conference, which brings together over 100 health care professionals every October to learn about advances in care and treatment and to share experiences. APF speaks each year, which provides an opportunity for us to highlight your concerns to the community of specialist nurses and other professionals.

Also, for the last two years we have worked with ILD/INN to educate nearly 500 nurses and health care professionals in diagnosis and treatment. We are planning to expand this programme over the next two years. One of the key findings of our 2018 patient survey was that almost one-third of PF patients do not have access to a specialist nurse. We also know that many ILD specialist nurses are often responsible for as many as 800 patients, while lung cancer nurses have far fewer patients - typically around 200. We will work with ILD/INN to collect evidence and highlight this issue to the NHS.

## Fantastic fundraisers

Yet again we have been amazed at the fantastic fundraising efforts going on around the country. Money raised for APF funds vital research and support or information for families. At APF we are lucky to support hundreds of runners, skydivers, cyclists, bakers, stall holders and people who rattle tins around the UK each year. Here we highlight just a few stories from 2019 so far – and give huge thanks to everyone who is fundraising.

**Lesley Cully**, pictured right, ran the London Marathon in memory of her mum, Frances, who died from IPF in December 2017. She completed the race in just 5 hours, 30 minutes. “It’s always been my dream to run the London Marathon,” said Lesley. “My mum always had it on the telly.” On the day Lesley had a temporary tattoo and supporters paid £5 for their name to be featured in the design. “I had 26 names including my lovely mum’s. I also ordered lots of balloons and APF banners for my family so I could see them in the crowd!”



**Philip Lovatt** was another London Marathon runner and managed a time of 4 hours, 31 minutes. His mum Carol’s brother- also called Philip - has IPF. He is currently on oxygen 24/7 but remains at home and has wonderful

support from the local NHS Hospital. Carol says, “Your charity has now become our charity and in future years will be the one which Philip promotes. The more research the better prospects of finding a cure, and the more that can be done to highlight the disease the better.”



**Leila and Collette Kellgren**, pictured left, ran the Liverpool Half Marathon for APF, raising £2,175 – more than doubling their target. They were also interviewed by the BBC, helping to raise awareness too. Their mum, Clare Dow, was diagnosed with IPF four years ago.

Also in Liverpool, **Linda Ryan** organised an amazing fundraising event in February. “I sold 140 tickets with a raffle, an auction, and most importantly dancing! It was a more subtle way of fundraising, where people left with a gentle awareness of pulmonary fibrosis. As I like to say, PF is in my life but it is not my life.” The whole event took a huge amount of organising and raised over £2,200 - a wonderful achievement from an inspirational lady.

Community Respiratory Specialist Nurse **Ella Purvis and her husband Craig** headed for northern Spain in May to walk 117km of the iconic Camino Frances in aid of APF. “The charity supported me to set up the first support group in Wiltshire last year, providing patients and families with the chance to meet others and learn more about managing their condition.” Ella and Craig soon overtook their £1,000 target.

Raising awareness of IPF is as important as raising funds, and **Gorleston Football Club** are doing just that. Their new tracksuits feature the APF logo and they made their first appearance at the Norfolk FA Junior Cup Final on 1st May. Club Chairman Alan Gordon commented, “As chairman of this fantastic club and living with IPF myself I am absolutely honoured and proud to help raise awareness through grass roots football. Thank you to Gorleston Football Club for making this possible.”



For many families, planning and organising a fundraising event can be a positive activity in difficult times. A run, cycle or cake sale can also be a great way to talk about the disease in positive way. If you’d like to talk through an idea or set up a fundraising event or challenge email Sharon on [fundraising@actionpulmonaryfibrosis.org](mailto:fundraising@actionpulmonaryfibrosis.org)



## They came. They ran. They raised £20,000!

The weekend of the Great Manchester Run in May saw a little bit of Manchester lit up by the distinctive purple running vests of Action for Pulmonary Fibrosis as 38 charity runners took to the streets.

They were running for loved ones lost and those fighting the disease and in memory of mums, dads, aunts, uncles and friends. It was a tough and emotional but joyful day as APF staff and a trustee joined supporters to compete in the half marathon and 10k races.

The money raised will go towards providing support and information to families here and now as well as funding research into effective treatments with the aim of finding a cure. The day was summed up by this runner: "We had an amazing time! A brilliant atmosphere with so much support. We will do our best to raise as much money as we can for your wonderful charity. Thank you for all the help and support you have given our family."



## Award recognises value of psychological support

Dr Karen Marshall, Nurse Consultant at Newcastle-Upon-Tyne Hospital and Newcastle University, has been named as the Respiratory Nurse of the Year in the British Journal of Nursing Awards.

Dr Marshall was recognised for her work using Cognitive Behavioural Therapy (CBT) to address the psychological impact of having a respiratory condition. She led a study of 236 patients with a diagnosis of mild to very severe pulmonary fibrosis. The study found that brief CBT sessions with respiratory nurses reduced anxiety for patients and resulted in less frequent use of A&E and hospital services.

"It is so frightening not being able to breathe but I think health care professionals don't address the psychological needs as well as they could. CBT techniques are a fantastic way to really work with patients to improve their difficulties even if in a small way. It's all about helping patients have the best quality of life they can."



Dr Karen Marshall, second right

You can find practical advice, interactive tools, videos and audio guides to help with your mental health at the NHS Moodzone - [www.nhs.uk/conditions/stress-anxiety-depression](http://www.nhs.uk/conditions/stress-anxiety-depression)

## Weekend in Paris? Let the train take the strain

You may think that boarding a Eurostar train for a weekend in Paris is beyond you if you have pulmonary fibrosis, but one of our readers has been in touch to recommend just such a holiday. She has IPF and her husband is a wheelchair user and, while she prefers not to be named, she says she would highly recommend the trip.

“We went for three nights to Paris and it was a wonderful and relaxing experience. Nothing was too much trouble for the people at Eurostar, from the moment we got to St Pancras to arriving at Paris Gare du Nord.”

Trains from much of the UK link up to London's St Pancras, and Eurostar provide an impressive support service for people with wheelchairs, mobility scooters or restricted mobility. Eurostar Assist has teams available at each station to help. You don't have to be registered disabled and you can take a small oxygen supply with you, but you must have a letter from your doctor confirming your use of oxygen. You also need to tell Eurostar the size of your wheelchair or mobility scooter as this may affect ticket prices.



**“We went for three nights to Paris and it was a wonderful and relaxing experience. Nothing was too much trouble for the people at Eurostar.”**



On arrival at the Eurostar terminal you will be escorted to priority seating in the departure lounge. When it's time for boarding you are helped to your seat and met at the other end and guided through arrivals. Those with reduced mobility but without a wheelchair will be helped to the train and through arrivals but must be capable of boarding and alighting themselves. Ramps are provided for wheelchairs.

A big bonus for wheelchair/mobility scooter users is that all the spaces are in Premier or Business Premier class but you only ever pay for the lowest cost standard ticket - £29 each way – for both the wheelchair user and companion. Sounds too good to be true? Our travellers say it worked like a dream.

“As soon as we arrived at the station someone came and took us to the front of the queue and showed us into the Business Class lounge where we could have free food and hot drinks, a cocktail and newspapers. It was amazing.”



On board our travellers were asked if they would like a taxi booked in advance. “This was our only mistake. The taxi was fine but we only realised when we took a taxi back to the station at the end of our trip that we'd paid double the fare. On reflection just pick up a taxi at the station – there are plenty with accessible entry for wheelchairs.”

Our couple also found getting around Paris to see the famous sights easy. “We stayed at the Marriott Hotel near the Eiffel Tower and there was a hop on hop off bus a short stroll away. We paid 12 Euros for a day ticket, and the people on board helped with a ramp. We also took a boat taxi on the Seine and saw the city from the river. Compared to the stress of airports it was a wonderfully relaxing and stress-free holiday.”

If you have questions about using oxygen on a trip to Paris – or anywhere else for that matter – you can speak to APF's respiratory nurse, Lucy, on our support line – 01223 785725. This is a call back service, so leave a message for a call you back within two days. The Pulmonary Fibrosis Trust also arranges portable oxygen concentrators for holidays and Chair, Peter Bryce, is a mine of information on organising oxygen abroad. You can call him on 07710 424746.

For more information see [www.eurostar.com/uk-en/travel-info/travel-planning/accessibility](http://www.eurostar.com/uk-en/travel-info/travel-planning/accessibility) and [www.eurostar.com/uk-en/book-wheelchair](http://www.eurostar.com/uk-en/book-wheelchair)

## Orchestra leader highlights IPF

Jenny Jones, leader and first violin of the British Police Symphony Orchestra, lost her father Christopher Fraser to IPF last year, aged 77. When the Orchestra decided to hold a Charity Gala Concert in May at the Royal Albert Hall, Jenny felt this would be an ideal opportunity to raise funds and awareness in his memory.

The family paid for an advert in the concert brochure to raise awareness of the disease and encourage people to donate. Jenny commented, "Action for Pulmonary Fibrosis has been a great support, both to my dad and to the family. Having a page in the brochure seemed like a good way to commemorate my dad's life and give something back to the charity."

The Orchestra celebrated 30 years of music making with the Gala Concert, which featured over 670 performers drawn from the police service throughout the UK, including massed choirs, pipe-bands and fanfare brass.

## Caring for carers

Unpaid carers face many challenges and provide fantastic support to patients, families and communities. Caring for someone can be demanding - physically, emotionally and financially. It can also be isolating so attending a support group can be a huge help. It's a place where you can share what's on your mind with others who understand what you are going through. You can read more about how some support groups are making this a reality in the Support Group round-up on page 4.

Here are some tips to help carers at your group:

- Invite your local carers centre to talk about what support they can provide. You can find your local centre at [www.carersuk.org/help-and-advice/get-support](http://www.carersuk.org/help-and-advice/get-support)
- Publish the local carers centre number in your newsletter or email correspondence to group members
- Offer the APF support line - 01223 785725 - for carers to use for expert advice and help
- Unpaid carers are entitled to a carer's assessment by their local council – you can find out more at [www.carersuk.org/help-and-advice](http://www.carersuk.org/help-and-advice)
- Carers centres can help you look after yourself, and signpost you to benefit advice and practical help.

Remember, being a carer can be hard work and you need to be at your best physically and mentally, so make sure you get the support you need.

## New hospital boasts state of the art facilities

The **Papworth Hospital Support Group** were given a special guided tour of the new Royal Papworth Hospital which opened recently.

It's the UK's largest specialist heart and lung hospital and was home to the first successful lung transplant in the UK in 1988. The multi-million-pound move to Cambridge's Bio Medical Campus puts it next to Addenbrooke's Hospital, an internationally-renowned teaching hospital and research centre.

More than 22,400 inpatients and day cases and 48,400 outpatients are treated at the hospital each year and over 900 people have received lung transplants since the first, 30 years ago. The Hospital also conducts world-renowned research into various lung diseases.

APF is partnering with the hospital to upgrade two rooms, which will be dedicated for use by pulmonary fibrosis patients. Each room will have a bed-settee so that loved ones can stay overnight, and special high-volume oxygen supplies for patients.

Support Group member Howard Wright said, "We were very pleased to have the opportunity to take a guided tour of the new building in Cambridge. We found an amazing and fascinating building with state of the art facilities for both inpatients and outpatients. This will have a major impact on PF patients from across the UK."



# Pulmonary Fibrosis Awareness Month - Join our campaign!

Pulmonary Fibrosis Awareness Month in September is a chance for everyone affected by the disease to work together to raise vital funds and knowledge of this cruel disease. Action for Pulmonary Fibrosis is spearheading the UK campaign to raise awareness of the disease with GPs, and our theme this year is:

## Listen To our Lungs

We've chosen this in response to what you told us. Our recent patient survey revealed that more than a third of patients with IPF are misdiagnosed and almost half not diagnosed correctly within six months of first visiting their GP with symptoms. Please help us improve these shocking statistics. If you would like to get involved – as an individual, a family or with your local support group – get in touch! We have lots of ideas and resources to help you raise funds and awareness in your community. We can help with:

- advice and contacts on how to reach out to GP surgeries in your area
- getting stories into your local media
- advice on posting on Facebook and Twitter
- posters, template letters, press releases and tee shirts.

Let's work together to make this happen. To register for an information pack, email us at [pfmonth@actionpulmonaryfibrosis.org](mailto:pfmonth@actionpulmonaryfibrosis.org) with your name, email address and whether you'd like a pack emailed or posted to you. Keep on eye on our website, Facebook page and Twitter for the latest news on the campaign.

## Great holiday offer at Great Yarmouth!

Holidaying abroad can be difficult for people with pulmonary fibrosis, but now there's a great alternative in the UK – and at a bargain price too. The Pulmonary Fibrosis Trust has bought a luxury mobile home on the Haven Seashore Holiday Park in Great Yarmouth and are making it available to patients and their families for a week or weekend for just a £40 booking fee. You also get a discount of 15% off everything on site, from newspapers to meals.

The site is right on the seafront and has a new indoor Water Park, improvements to the bar and eating areas and new indoor soft play and outdoor play areas for children. The scheme is the brainchild of Pulmonary Fibrosis Trust Trustees and their Chair Peter Bryce. PFT Ambassador Sarah Douglas has set up a patient journal in the caravan so visitors can leave tips and notes for each other, as well as a caravan folder with lots of tourist information and money off vouchers for local attractions.



Peter commented, "We already provide portable oxygen for people who are travelling abroad, and then we thought, what about those who can't even afford a holiday in the UK? By keeping the cost to a minimum we hope we'll be able to fill the home throughout the season."

To find out more about taking a Great Yarmouth break, simply visit [www.pulmonaryfibrosistrust.org](http://www.pulmonaryfibrosistrust.org)

### Contact us

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