



50th support group for patients & families

As the 50th support group set up to help those affected by pulmonary fibrosis was launched at Northwick Park Hospital in Harrow recently Action for Pulmonary Fibrosis announced ambitious plans to double the number of groups to 100 by 2020.

"The increase in the number of groups over the past few years has been quite incredible, going from around half a dozen just five years ago to 50."

The support group was inspired by pharmacist Sandeep Bansal, who lost her father to IPF in 2016. "Seeing Dad suffer the way he did has motivated me to do something to help others who have pulmonary fibrosis so in the future they won't have to go through what we did," says Sandeep who was supported in setting up the group by Dr. Arnab Datta, Consultant Physician in Respiratory Medicine and APF.

Speaking about her father, Sandeep said: "The thing we all struggled with most was the lack of awareness of Pulmonary Fibrosis. Dad started to become seriously ill in December 2015, but earlier that year Mum had been diagnosed with stage four breast cancer. When Dad needed around the clock care, Mum did not hesitate. My parents lost their battle within months of each other.

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Record number of new support groups!

We've had a fantastic number of group launches in the last six months, all have which have been supported by APF. We want to make sure that all patients and families can easily get to a support group, which is why it is one of our top priorities. We've travelled all over the UK to help groups get started and to take part in their launch days. Mid-Essex, Herefordshire, Fife and Tayside, Worcestershire, Guys and St Thomas', Gloucester and Bolton have all launched recently and these groups are now thriving.



Launch of the Mid-Essex Support Group



Inside...

Welcome... Support group news... Coping with cough... Research updates... Voice of the Patient Council... Fundraising activities... Health tips... Living with Pulmonary Fibrosis... New APF team members...

welcome



Welcome to the first issue of APF's newsletter which is reaching out to PF support groups across the UK.

The aim of the newsletter is to bring the PF community together by sharing ideas and providing a network to support one another. We would like you to see this as your newsletter, so please let us know what you think, and send us your suggestions, stories and pictures for future issues.

I'm Lorna McLauchlan, the National Support Groups Co-ordinator for Action for Pulmonary Fibrosis. I've worked in respiratory care for 32 years, mostly as a respiratory ILD nurse specialist. I set up my first support group in 1995 and quickly realised how valuable sharing common experiences can be. Working with APF has enabled me to continue to support the setting up of new groups and to see first-hand the huge benefits this has for patients, their relatives and friends.

We hope you enjoy the newsletter and find it useful in developing and getting the most out of your group. In this first issue you'll read lots of support group updates, some practical tips from a health professional and ideas about living with PF from a patient's point of view.

We look forward to hearing from you.

Lorna McLauchlan

- from Lorna and the APF team

50th group launch continued...

Key milestone for support groups

"We are a Punjabi Sikh family who believe in sharing the good times as well as the sad times. Watching my Mum rise to the challenge has inspired me to take this step. If she was able to help make our Dad's life better whilst being unwell herself, then surely I can continue her good work."

APF Chair, Steve Jones said: "As a patient I know how valuable the support of others is and by working together we are determined to improve the care provided to pulmonary fibrosis patients and their families, wherever they live in the UK. Our goal is that no patient lives more than one hour away from a support group."



Get online and get social



Using social media is a great way to connect with patients, families and healthcare professionals.

Have you thought about setting up a Facebook page or creating a Twitter account? Getting online means you can raise the profile of your group, recruit new members and share meeting dates and updates. It is also a great way to learn about what other groups are doing and to share ideas!

Many groups are already "getting social", such as Bolton, Nottingham, Manchester and St George's. If you would like any help or advice in setting up a Facebook page or Twitter account then please get in touch with our Fundraising & Marketing Co-ordinator Alex Croft by emailing -

alex@actionpulmonaryfibrosis.org

Growing the groups - Tameside

Support groups are a vital way of helping people living with pulmonary fibrosis. However, due to the relatively rare nature of the condition, people may find themselves a long way from a local group.

APF Chair Steve Jones says, "APF's vision is to have 100 groups across the country so that every IPF patient is within an hour of a group – which will be a real challenge in more remote areas!"

He advocates the hub and spoke model, where well established groups linked to specialist centres support new groups in smaller towns with general hospitals. Papworth of which he is Secretary, supports new Groups in Bedford, Stevenage and Chelmsford. This 'regional network' supports joint activities. A joint Patient Information Day is planned near Cambridge in the summer. A similar network is starting to emerge in West Wales.

"APF's vision is to have 100 groups across the country so that every IPF patient is within an hour of a group."

Further North, the hub and spoke approach is also bearing fruit. The Manchester Group was set up by doctors from the specialist Interstitial Lung Disease unit at Wythenshawe Hospital. It has been going for 15 years and is currently led by Dennis Barber.

In January this year Clive Green, a retired firefighter from Ashton-under-Lyne, attended the Group and found it inspiring. However, the long journey to Manchester and parking difficulties at the Hospital were a little off-putting. He spoke to Dennis, asking if he'd mind if he tried to set up a more local group in Tameside. Dennis's response was enthusiastic:

"I said, if you can find somewhere, sort out some information and get people to turn up, then why not? We can pass on people who give a talk here, keep in touch and share ideas."

Clive was able to secure a free community room at the local Fire Station. He spoke to his Respiratory Nurse, the local Breatheasy Group and posted on Facebook, and soon had a lot of interest. Following an event in Stockport supported by the British Lung Foundation he was inundated!

With commitment from people like Dennis and Clive, Steve's vision of 100 Groups might not be so far away after all.



Fantastic Support for IPF world week!

IPF World Week last September saw the entire IPF community come together to raise awareness of the disease with local support groups raising over £20,000 for APF!

Health Care Professionals and support group members held awareness stands in their hospitals and we sent out over 3000 IPF Week wristbands and other resources to supporters to help spread the word. It really was a team effort and we had the most successful awareness week yet.

During IPF week we :

- Launched The APF Mike Bray Fellowship in Idiopathic Pulmonary Fibrosis which will be awarded over three years to an outstanding research project
- Produced new materials to support healthcare professionals in helping patients and families
- Held a Voice of the Patient event and listened to and learned from patients, families and carers about how we could best support them.

We also joined the global campaign 'Listen for the Sounds of IPF' with the European Idiopathic Pulmonary Fibrosis and Related Disorders Federation. The campaign highlighted the importance of recognising early signs and symptoms of IPF and of accelerating patient referral to a respiratory specialist.

Thank you to everyone who wore a wristband, took part in an event, baked a cake or talked about IPF on social media!



Claire Wright (centre) raised £12,000 in IPF Week in memory of her Dad, Chris Heap



Nottingham Support Group

The Nottingham PF Support Group has been going for three years now and was started by Respiratory Nurse Julie Morgan from Nottingham's Queens Medical Centre. When Julie retired last year it was decided to set up a committee to share the work. We are grateful that Julie stayed on as Chair and she keeps us all in check and organised!

We have our own Facebook page which Julie regularly updates. Patient Malcolm Tait, who travels from Skegness to Nottingham for each meeting, took on the role of treasurer and has made a great job of it. We raise money by having a raffle every meeting and members also contribute through fundraising events.

Our group likes a good mix of informative and helpful sessions and social events. In the

past year we have had talks from respiratory specialists, dieticians, and the local hospice and we've really enjoyed a boat trip down the River Trent, seated yoga, singing, Afternoon Tea at a local beauty spot and quizzes. We try really hard to promote a positive and cheerful atmosphere and 'having a laugh' is a top priority.

Our advice?

When we started we didn't have a bank account (we do now) and that presented problems when people wanted to give us donations and grants or fundraise for the group. Our advice is get a bank account set up immediately. It's easy.

And encourage wives, husbands, friends who may have lost someone to attend or continue to attend the group to give them ongoing support.



Living with Pulmonary Fibrosis Five-a-Day and a Four-Legged Friend

No-one knows better than patients themselves what it's like to live with a disease like IPF. Our Living with Pulmonary Fibrosis series will feature one patient's approach to managing the condition, and our first contributor is Sue from Derbyshire.

Sue was diagnosed two years ago, several months after her first symptoms appeared while on holiday in Wales. While she has bad days as well as good ones, she is better now than when first diagnosed, and puts this down to two things – fruit and exercise.

We all know that fruit and veg are good for us, and many people try to get their 'five-a-day'. Luckily Sue finds this easy, as she loves fruit. "I go to the market and buy whatever they have – lychees, plums, mango – I think I could almost live on fruit in the summertime!"

Sue also adds healthy supplements to her diet, such as chia seeds in her salads and yoghurt and zaggara, a concentrated mix of green vegetables. As well as a good diet, Sue also enjoys plenty of exercise although knows that this can be difficult for some people.

"I do two good walks a day, which amounts to 12 or 15 miles a week. I take my lovely dog, Pancake –

who does very well at 13 years old! It makes a real difference having a dog to walk, and I like meeting people and enjoying the flowers and the birds as well as the walk itself."

Sue lives alone so is used to having to do things for herself, which she thinks has also helped her to manage her condition.

"If I want a cup of tea I have to make it myself, so I think it's made me feel I just have to get on with things. We all have bad days, but when it's good I can get out and have a lovely walk or do some baking for my family, which I really enjoy too."

Everyone has their own way of coping, but for Sue it's definitely five-a-day and her four legged friend that makes all the difference.



Sue with daughter Elizabeth

Health Tips

Coping with Cough

Every issue we'll be featuring some practical tips from a health professional. The Norfolk and Norwich Support Group found a recent talk by Respiratory Nurse Consultant Sandra Olive very useful, so here is some of her advice about coping with cough :

Many people with fibrosis struggle with a troublesome cough and it can be a difficult and debilitating symptom to manage.

A dry, tickly cough is common and can be tiring and irritating for both the person with the cough and those around them. When there is no phlegm it is useful to learn some 'cough suppression' techniques:

- Have a drink handy to take small sips (either just water or something soothing like warm honey and lemon).
- Try sucking a sweet.
- Cover your mouth with your hand and try to breathe through your nose to warm and moisten the air so that it is less irritating to the airways.
- Hold your breath for a few moments and try swallowing your saliva.
- Keep the breathing slow and gentle if you can.
- Simple linctus or codeine linctus (try in a little hot water) helps some people.



Bridgend Support Group

Bridgend IPF Support Group is held monthly at the local tennis club. The group includes patients and relatives and is a welcoming supportive environment that provides free teas and coffees, useful education talks and direct contact with the specialist nurses Natalie and Rebecca.

Each meeting we have an (optional!) half hour of Thai Chi, which is open to both patients and relatives and is aimed to provide some relaxing breathing and movement techniques to help practice breathing control and gentle exercise.

However, if you have a cough that produces phlegm, it is better not to suppress it. Use a technique called the Active Cycle of Breathing Technique to help loosen and clear the phlegm. ACBT is a five stage breathing pattern and it is good to practice this regularly to clear your chest.

“it can be a difficult and debilitating symptom to manage”



Stage 1 – relaxed gentle breathing: through the nose if possible, relaxed shoulders, tummy rising with the breath in.

Stage 2 – deep breathing: slowly through the nose, keeping the shoulders relaxed, holding for a couple of seconds if you can, then letting the breath out gently through the mouth. Repeat 3 or 4 times to get air behind any phlegm in the airways and begin to move it upwards.

Stage 3 – repeat stage 1: relaxed breathing.

Stage 4 – huffing: take a medium breath in and then breath out fast through your open mouth, as if misting up a mirror. Repeat with a larger breath but just once to avoid triggering a coughing bout before the phlegm is in the upper airway.

Stage 5 – cough: if it feels as though there is phlegm to clear, take a deep breath and cough once or twice.

This cycle can be repeated until the phlegm is cleared, going back to the relaxed breathing each time. Make sure you don't get dehydrated as this can make phlegm thicker, stickier and more difficult to cough up.

Generally speaking, it's also important to treat any gastric acid reflux or indigestion, which often makes coughing worse, and to check your medication in case there are any 'cough triggers'.

Talk to your doctor or respiratory nurse if cough is a major bother for you – they might be able to give you some general advice or refer you to a physiotherapist for more specific help.

Over the past year the group has participated in fundraising for APF and promoted the charity in activities such as Cardiff 10k, Barry Island New Year's Day dip, Walking Football, cake sales, supporting World IPF week to name but a few!

We have a Twitter and Facebook account that provides a platform to read about current research, positive coping strategies and links to what is happening in the world of pulmonary fibrosis.

Natalie Murray,
ILD Nurse Specialist



Our First Year: Bedford Pulmonary Fibrosis Support Group

How did it start? I used to attend the Papworth Support Group – which involved a 20 mile drive from my home in Bedford – and at one meeting a Bedford Pulmonary Rehab Team member said, “For years I’ve wanted to set up a Bedford Support Group”. My wife responded “my husband will help.” I had been volunteered! What followed were three meetings with members of the Pulmonary Rehabilitation Team and we distilled the following principles:

- The group should be Patient/Carer led with a strong link to the hospital.
- Any Committee arrangement must have a hospital appointed representative.
- Six Group meetings a year held in alternate months.

The Inaugural meeting was held on 20th June 2017 at the Jubilation Centre, Bedford, chaired by Nicola Rowe, Lead of the Rehab Team – who gave a talk on pulmonary rehabilitation. We also had presentations from Consultant Physician Dr Enson Thomas and APF Chair, Steve Jones. It was a very successful event with thirty-four attendees. We agreed that our annual programme would be a mix of general interest subjects and, when appropriate, medical topics. We also agreed a simple format for all group meetings:

2.30pm – Assemble, chat, exchange experience etc. - Tea, Coffee and Biscuits available

3.00pm – Welcome, Group Business - Talk/ Presentation, Questions

3.45pm - Raffle and Finish

Group Meetings have so far have covered “Travelling with Pulmonary Fibrosis” to - at our December meeting – The Bedford Carers Choir singing Christmas carols. This was probably the highlight of the year. We have up to 34 patients and family members at each meeting and members say they really appreciate the thirty minutes at the start as, “it enables us to chat, exchange experiences and meet new people.”

In order to bring regularity to the group a Constitution has been drafted for consideration and acceptance at this year’s AGM.

We published our 2018 programme, statement of aims, location and contact details on a small card which can be kept in a pocket, handbag or pinned to a notice board. It is also on display in the Chest Clinic and GP Surgeries, one of which has published it in their surgery newsletter. We also produced a poster for display anywhere - libraries, churches, supermarkets and garden centres. We are contacting local newspapers, magazines and local radio for publicity. Topics for 2019 are being considered as are joint ventures with neighbouring groups. We also plan to look at how best we could use social media to promote the group and raise awareness of Pulmonary Fibrosis.

On a personal note it has been very enjoyable getting the group up and running, although you do have to be careful that it doesn’t take over your life. My wife and I find ourselves discussing the group at breakfast! All worthwhile, though.

Our Top Tip: Foster a good relationship with your local pulmonary rehab team – they will be invaluable to you.

Neil Curran: Chair

Manchester Support Group member leaves £20,000 to APF

Ray Stubbs, a member of the Manchester Support Group who passed away from IPF last May, has left a £20,000 bequest in his will for Action for Pulmonary Fibrosis, specifically to be used for research.

The cheque was presented to APF’s Support Group Co-ordinator, Lorna McLauchlan, by Mr Stubbs’ friend Sue Turner, at a recent meeting of the Manchester Group, led by Dennis Barber.

“IPF had a profound effect on Ray’s energetic lifestyle, but he was very appreciative of the help and support of the Lung Disease Unit at Wythenshawe Hospital and of the support group and its members, ” said Sue.

160 mile round-trip to support group in Scotland

The **Grampian Pulmonary Fibrosis Support Group** was set up in 2015 and currently has 30 members with around 15 regularly attending our bi-monthly meetings. Members travel from far and wide, with our most adventurous member travelling almost 160 miles round trip to attend! We organise fundraising events to cover costs of running the group, such as refreshments and hire of a venue. We will also cover travel costs for any member who would otherwise be unable to make their way to the meetings. We've had speakers on pulmonary rehabilitation and oxygen therapy but members indicated that not all talks need to be medically related so our next speaker is Howard Drysdale, the Port Chaplain at Aberdeen Harbour, who will speak about his work with seafarers from all over the world. Our most challenging time since the inception, was the untimely departure of our wonderful secretary and we struggled for a year with nobody coming forward to fill the position. Thankfully, a lovely volunteer eventually came forward and joined the committee in January.

Catherine Bamlett
Respiratory Specialist Nurse ILD



Leeds Area Pulmonary Fibrosis Support Group

We've been meeting every two months since November 2015 and around 40 members attend on a regular basis. Our members have IPF, PF and other lung diseases. We are very grateful to Action for Pulmonary Fibrosis and the British Lung Foundation who each issued a generous grant to help us to get started.

Our meeting room is at a Rugby Club which is quite expensive but the facilities are great – we have the use of a projector and screen and a microphone, and two water boilers so that we can organise our own refreshments. Plenty of car parking space and level entry to the premises is important. We have a donations box by the door and some of our members bring items to raffle, drawn at the meeting and, because of this, we can normally cover the cost of the room on the day.

In December 2016, our Chairman, Tony Gowland, was admitted to hospital for a double lung transplant, long awaited, and since then our Secretary has been wearing two hats but at this January's meeting we welcomed Imelda Redman as our new Chair. Imelda is a published author and has written text books for AQA and GCSE to higher level, under the name of Imelda Pilgrim. She is Chief Examiner for both Exam Boards.

Our Top Tip

Start a newsletter. From the beginning we issued a newsletter, covering the subjects presented by our Speakers, with a few photos thrown in. What began as a struggle to fill two pages is now a problem squeezing our information into three! This is a really important method of circulating news and information to all our members – mostly by email, a few by post. It's also a way of communicating with those of our members who are unable to attend the meetings in person, for whatever reason. Our members seem to enjoy and appreciate it!

We wish Action for Pulmonary Fibrosis every success with their newsletter!

Christine Cole, Secretary

"The Group gave him the opportunity to discuss his concerns with people suffering the same symptoms and provided him with helpful advice on how others were coping. Although it is a sad occasion to lose a good friend and neighbour like Ray, it is also a privilege to represent him at the support group today and to hand over to Lorna a cheque for £20,000, which Ray generously bequeathed to APF, hoping that ongoing research will one day find the cure that Ray himself was searching for."



Research Updates

Research Grant in memory of late APF Chairman Mike Bray

The APF Mike Bray Research Fellowship in Idiopathic Pulmonary Fibrosis has been launched in memory of the charity's founder and former chairman, who passed away in 2017. Mike, an IPF patient, had a single lung transplant at the age of 68 and from then until his death six years later worked tirelessly on behalf of other patients.

“Made possible purely through the commitment and generosity of individual fundraisers”



The Fellowship will be financed by a £300,000 grant that will be awarded over three years to an outstanding research project, which enhances understanding of the causes of IPF or advances treatments. Applications are currently being processed and we will have more news on the chosen research project later in the year.

The grant has been made possible purely through the commitment and generosity of individual fundraisers and those who have made donations in memory of a loved one, often at a very difficult time in their own lives. APF supporters told us how important it was that the money they raised went towards research – hence the Fellowship.

Mike's wife, APF Trustee Mrs Elizabeth Bray said:

“Mike would have been shocked but delighted to have a research project in his name. Being a patient and understanding so well the effects of IPF on the patient, their family and friends, after his transplant he worked hard to raise awareness and to encourage actions to improve the treatment and care for all IPF patients. This grant will help to achieve those improvements. Thank you to all who have made it possible.”



Our Voice of the Patient Council needs you!

If you are a patient with pulmonary fibrosis then we want to hear from you. Everything we do as a charity is guided by patients and carers. To make that bold claim we need to listen. You and your family can have a real influence on our work by joining our Voice of the Patient Council, a consultative group which helps us make crucial decisions.

Council members get together once a year for a day-long conference but we also contact them throughout the year by email. Recently we have asked Council members to review our Support Group Guide which helps new groups to get started. Their feedback and advice has been really useful. We also asked them to look at our website content and give us feedback on what was good and what needed improving or adding to, and we even asked for their input into this new newsletter.

To join just visit our website www.actionpulmonaryfibrosis.org and you will see the sign-up section on our Homepage. We'd love to hear your voice. Join us.



The Norwich Medical School recruited their 300th patient to the EME-TIPAC trial on treating pulmonary fibrosis with co-trimoxazole (an antibiotic).

Norwich Clinical Trials Unit is coordinating the nationwide trial, which is taking place at 43 centres across the UK. The study aims to discover whether taking co-trimoxazole, alongside other treatments, improves life expectancy and reduces the chances of IPF patients being admitted to hospital.





A Star Studded Night in Aid of APF

A Sunday night in October last year saw a glittering charity event take place for one night only – Live at the London Cabaret hosted by Gok Wan, in aid of Action for Pulmonary Fibrosis.

The concert was spearheaded by West End performer Becky Herszenhorn who is currently appearing in 42nd Street at the Theatre Royal, Drury Lane. Becky recently lost her grandfather Norman Gibbs to Pulmonary Fibrosis and wanted to do something to celebrate his life and raise money for the charity.

The evening was a huge success with stars performing to a sellout audience at the London Cabaret Club. Headline acts included John Partridge, Ben Adams and Joanne Clifton alongside some fantastic West End stars who gave their time to support Becky and APF.

Senior Operations Manager for Action for Pulmonary Fibrosis, Roxane Caplan, who attended the event said: "On behalf of Action for Pulmonary Fibrosis, we would like to thank all the stars of London's West End who came out and performed Live at the London Cabaret Club last night to raise awareness of Idiopathic Pulmonary Fibrosis and much needed funds for APF. It was a wonderful evening, full of glamour and showmanship, and we are very grateful for their support."

Westminster Event Highlights

IPF was the subject of a Parliamentary event at Westminster in December, and Action for Pulmonary Fibrosis were delighted to take part.

The event brought together those living with IPF and politicians from all parties to raise awareness of the disease. Maggie Throup, MP for Ilkeston in Derbyshire, whose mother passed away from the illness, hosted a meeting to hear patients' stories and discuss what action could be taken to improve care and diagnosis.

Participants raised the issue of gaps in early stage treatment and care - one person described the current situation as the equivalent to telling a cancer patient they cannot have treatment until their tumour increases in size.

Clare Beckett, 38, from Cambridge said: "Today's event has been very emotional and informative. These type of initiatives are great platforms for people with IPF to come together and support each other. The toughest decision in my life has been having to tell my family about my condition as we have a family history of pulmonary fibrosis and my mum died from it. But I am very lucky to be surrounded by family and friends that have offered me unconditional support."

Maggie Throup MP said: "I'm delighted to be championing people with IPF. I know from first-hand experience with my mother's illness how life-changing a diagnosis of IPF can be, and I have been inspired by those who have attended today to share their experiences."



Westminster round-table event led by MP Maggie Throup (centre)

Even More Support for Support Groups!

Physiotherapist Laura Bygrave has joined APF as Support Group Co-ordinator for the South East. Laura qualified in 2013 and worked at Bedford Hospital. After working with the Pulmonary Rehab Team providing maternity cover, she realised this was an area she was particularly interested in and she moved to the Hertfordshire Team two years ago.

Laura enjoyed working with IPF patients, but felt that there wasn't much information or support. She therefore set up a support group in Stevenage which has now been active for over a year.

"I really liked setting up the Stevenage Group, so when I saw the APF role I decided to apply. I had seen what a difference the Group made, and wanted to expand my role and help other people to do the same in their area," she told us.

Laura will continue working as a physiotherapist, and is also on the committee of the ILD Interdisciplinary Network. She will be working with APF's existing Support Group Co-ordinator, Lorna McLauchlan, but will focus on London and the South East.



"I want to set up as many Groups as I can, and make sure they are supported and well attended."

New Trustee Joins APF

The newest addition to APF's Board of Trustees is Stephen Morgan-Hyland who, in keeping with the charity's policy of recruiting trustees with personal or professional connections with pulmonary fibrosis, sadly lost his dad, Tony to IPF in 2017.



Stephen will bring a wealth of commercial and strategic talent to the charity. He has over 20 years' experience as a planning and property consultant and is a Director at a leading planning and economics consultancy in Manchester. He is involved with some of the largest commercial development projects in the UK.

"APF does such a magnificent job in raising awareness of IPF and providing support to those affected by the condition."

He is a keen runner, and can often be seen in competitive races flying the Action for Pulmonary Fibrosis flag.

He told us, "APF does such a magnificent job in raising awareness of IPF and providing support to those affected by the condition. When my dad died it was a natural step for me to become involved with the charity in his memory, and contribute to the fantastic achievements to date. He died after having the illness for a number of years but was diagnosed too late for any longterm treatment. I intend to work with the other APF Trustees and supporters of APF in the interests of maximising the number of cases where early diagnosis is made."

Fundraising Updates

Hi, I'm Alex Croft, and I manage fundraising for APF and look after all of our wonderful fundraisers. As a small charity we rely on the incredible support, hard work, and generosity of our supporters who take on lots of amazing and eclectic challenges to raise funds and awareness for pulmonary fibrosis.

This year, for the first time ever, we are taking part in a big run - I'm delighted to announce that Action for Pulmonary Fibrosis have 25 runners in the Great Manchester Run which takes place on Sunday 20th May.

Another exciting and important event in our fundraising and awareness calendar is IPF World Week, which as you know, takes place every year in September.

It is an opportunity for the entire pulmonary fibrosis community to come together to raise awareness and funds. We are busy planning our IPF World Week campaign and events and we would love for you to get involved by planning a support group event.



I'm here to help so if you need any support or advice then please email me alex@actionpulmonaryfibrosis.org.

We will have IPF World Week branded merchandise available from August – last year our #IPFweek wristbands proved a huge success!

Fantastic Fundraising Activities and Support Group Events!



Pen Y Fan trek
Gayle Hall and friends walked up the gruelling Pen Y Fan, the highest peak in Wales, in honour of their friend Marie Piles, during IPF World Week.



Awareness stand in IPF World Week!
Royal Exeter and Devon Hospital raised awareness during IPF Week 2017 alongside APF trustee Howard Almond.

Grampian group support IPF World Week
Grampian Pulmonary Fibrosis Support Group arranged an awareness stand in IPF Week!



TrekFest The Peaks challenge
Olivia Hall completed TrekFest 2017 with her sister Rosary and Dad Stephen and raised £870.00 for APF!



Malcolm Hyland with Mayor & Mayoress of Fylde
Malcolm organised a sponsored walk from the Windmill in Lytham St Annes to Blackpool Tower walking 8.5 miles!



Half Marathon for APF!
Yasmin Hussein completed the Kingston Half Marathon and raised a fantastic £495.00!

Nurse support in IPF World Week
The nurses at the East & North Hertfordshire NHS Trust hospital raised awareness in IPF Week!



Walk with Mike
Angela Verinder organised a sponsored walk in Liverpool for her Dad and raised an amazing £2800 for APF!



Tunes in Two Cities
Ann and Stan Dunford Smith of the band Mulholland organised two concerts in York and Hull and raised a fantastic £1200 for APF!



Manchester Group
The group, run by Dennis Barber, held a cake stall at Wythenshawe Hospital in South Manchester and raised £700!

IPF world week 2018

We'd love you to get involved with IPF World Week this year, which is due to take place in September. We will be having a Voice of the Patient and fundraiser event, as well as raising lots of awareness!

Last year we had amazing support from fundraisers, support groups and health care professionals and we would love to make this year's IPF World Week even better!

If you want any help planning an event during IPF week or if you'd like any merchandise please contact Alex Croft for more details - alex@actionpulmonaryfibrosis.org

Do you want to feature in our next newsletter?

We are always looking for interesting stories, helpful tips and lovely photos to feature in our newsletter. We would love to hear from you if you have a story you want to share with us.

If you would like to be included in the next newsletter or if you have any feedback about this edition then please email Debbie Jackson debbie@djprm.co.uk or call her on - 07498 056979

Your nearest support group is:

Meeting dates:

Find us online

Website
actionpulmonaryfibrosis.org

Facebook
facebook.com/actionpulmonaryfibrosis

Twitter
twitter.com/actionpfcharity

Contact us

General enquiries
info@actionpulmonaryfibrosis.org
01543 442 152

Support groups
lorna@actionpulmonaryfibrosis.org
07914 426 269

Fundraising
alex@actionpulmonaryfibrosis.org



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