



# Hope, help and a voice for pulmonary fibrosis

Our work: January 2016 - December 2016

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Thank you to Boehringer Ingelheim, the founding partner of the British Lung Foundation IPF programme. The company had no influence over the activities or the content of this report.

## Giving a voice to pulmonary fibrosis



Pulmonary fibrosis is a priority for us. The voices of those living with pulmonary fibrosis must be heard - and acted on by policy makers and the health services.

Pulmonary fibrosis has a huge impact on people's lives. Many different conditions come under this term; they all cause scar tissue to build up in the lungs, which makes them stiff and breathing difficult. Patients and their families tell us of their fights to get the support and care they desperately need. This needs to change.

From our research this year, we found that idiopathic pulmonary fibrosis (IPF) is twice as common in the UK as was previously thought. Over 32,000 people are living with it and sadly just over 5,000 people die from it every year. We're committed to increasing research into pulmonary fibrosis. By the end of 2017, we'll have funded an extra £300,000, bringing our total investment to over £2 million. A big thank you to all our supporters for making this possible. We want to do more!

In 2016 we worked with our patient representatives and supporters to get your voice heard. We campaigned for improved services with policy makers and politicians. We raised awareness in the press and the public. And we supported those who needed help through our helpline and support groups.

We share your commitment to giving hope, help and a voice to everyone living with pulmonary fibrosis. Much was achieved in 2016 and - with your help - we're determined to achieve more in 2017 and beyond.

A handwritten signature in black ink, appearing to read 'Penny Woods', with a long horizontal stroke extending to the right.

Dr Penny Woods

Chief Executive

## Executive summary

This year we broadened our scope beyond idiopathic pulmonary fibrosis (IPF). We now support everyone living with any type of pulmonary fibrosis.

We published research in 2016<sup>1</sup> which told us that twice as many people in the UK live with IPF as previously thought - around 32,500.

We want to make sure that people living with pulmonary fibrosis, their family and carers have the information and support they need, as well as high quality services. Thanks to our supporters' fantastic fundraising, we also fund new research projects every year.

**Read Marie's story on page 22**

### **Falling from 13,000 feet to fight IPF**

“Les was everything to me. Losing him was so hard. Pulmonary fibrosis is such an insidious, shockingly cruel condition. That’s why I decided to start fundraising. If the money can go to research which can help other people, then it’s worthwhile.”



Patient voice is part of everything we do. This includes our pulmonary fibrosis patient and carer representatives in our Patient Think Tank. They all give invaluable advice and insightful feedback to drive our strategy.

In 2016, we launched new patient information on pulmonary fibrosis - in print and online. Nearly two-thirds of local pulmonary fibrosis support groups attended our two networking conferences. One in ten calls answered by our helpline are about pulmonary fibrosis.

Our potential media reach in 2016 increased to 180 million people. We influenced ILD services across the UK, including representing the patient voice in the new ILD service proposal for Wales. The Welsh government funded this new service in April.

So much has been achieved, yet there is still so much more to do. We'll continue to work with patients and their families, health care professionals and policy makers to improve support and services across the UK.

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<sup>1</sup> BLF, 2016, Battle for breath, [blf.org.uk/what-we-do/our-research/the-battle-for-breath-2016](http://blf.org.uk/what-we-do/our-research/the-battle-for-breath-2016)

## Introduction

One of our priorities across respiratory disease is pulmonary fibrosis. In 2013 we decided to focus initially on idiopathic pulmonary fibrosis (IPF), which is the most common type. We've now broadened our scope to include all types of pulmonary fibrosis. We wanted to do this as we felt we could then support many more people.

The length of time that people live after being diagnosed with IPF varies. Studies before the availability of specific treatments showed that almost half died within three years of their diagnosis. Despite new treatments that slow progression, there is still no cure. For a small number of people, having a lung transplant may be an option.

Our new research published in 2016<sup>2</sup> found that around 32,500 people in the UK live with IPF - far more than previously thought. The prevalence rate is more than double the National Institute of Health and Care Excellence's (NICE) estimate.

Living with pulmonary fibrosis can have a huge impact on the quality of life of patients, their carers and family. Specialist health services may be difficult to access, and it can be difficult to meet others in the same situation.

We want to make sure that:

- people living with pulmonary fibrosis, their family and carers have the information and support they need to understand their illness, make decisions and make the most of their lives.
- we influence and shape NHS and other services to ensure they are accessible, integrated, appropriated and evidence based.

Thanks to all the fundraising efforts of our supporters, we also continue to fund new research into pulmonary fibrosis every year.

## What is pulmonary fibrosis?

Pulmonary fibrosis is a term that covers many different conditions that cause scar tissue to build up in your lungs. This build-up of scar tissue, which makes your lungs stiff, is called fibrosis.

Pulmonary fibrosis is a type of interstitial lung disease (ILD). 'Interstitial' means the disease affects the interstitium, the lace-like network of tissue that supports the air sacs in your lungs. There are more than 200 different ILDs. In ILDs, there can be scarring in your lungs or inflammation in your lungs.

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<sup>2</sup> BLF, 2016, Battle for Breath, [blf.org.uk/what-we-do/our-research/the-battle-for-breath-2016](http://blf.org.uk/what-we-do/our-research/the-battle-for-breath-2016)

## Summary of our successes, 2016

### Patient voice

- Over a quarter of our Patient Think Tank have or care for someone with pulmonary fibrosis. They provide advice and feedback on key strategic decisions, and their ideas help inform all our work from research to media.

### Providing information and support

- We launched our new *Living with pulmonary fibrosis* booklet explaining what pulmonary fibrosis is, diagnosis and treatments. This booklet has the first clear lay explanation of terminology and classification of ILDs, and a new section on breathing techniques.
- There were over 250,000 visits over the year to our IPF web information. Our new pulmonary fibrosis web hub launched in September 2016 had almost 50,000 visits in three months.
- Our information on living with IPF towards the end of life is now ranking at the top of Google search results internationally for relevant search terms.
- We organised two pulmonary fibrosis support group networking conferences where members shared their valuable experiences and learnt more about running a support group. This reached 64% of local pulmonary fibrosis support groups.

### Raising awareness and influencing

- We generated over 100 new articles on pulmonary fibrosis in the media, with a potential media reach of 180 million.
- We held an ILD care pathway roundtable with 30 experts from across the UK representing specialist ILD services, general practice, patient and family members, commissioners and other pulmonary fibrosis charities.
- Our Welsh team represented the patient perspective in the development of a new ILD service proposal for Wales and campaigned for implementation. This was funded by the Welsh Government in April 2016.

### Research

- We published new comprehensive data on IPF which found that 32,500 people are living with IPF in the UK - twice as many as previously thought.
- We've funded five new ILD research studies in our financial year 2015-16, including research into singing for breathing and studies to further understand disease mechanisms.

## Patient voice

We build the patient voice into everything we do. We recruit new volunteers to our Patient Think Tank every two years. This group provides advice and feedback on key strategic decisions that we make and resources that we produce. Currently over a quarter of our patient or carer volunteers on the Think Tank have a connection to pulmonary fibrosis. Conditions include IPF, sarcoidosis and NSIP. We also have a former carer.

We have a research committee made up of patient and health care professional representatives who help decide what research we fund.

This year we also trained new media volunteers at a media day in the summer. Half of the new volunteers either have, or care for someone with, pulmonary fibrosis. Conditions include IPF, sarcoidosis and hypersensitivity pneumonitis. Media volunteers play a vital role when we raise awareness through the press. We ask our volunteers to speak at a variety of events including health care professional conferences and patient events.

Regionally we regularly seek advice from patients on our regional forums and from our network of support groups.

If you'd like to become involved and support the work we do then we'd love to hear from you at [patientvoice@blf.org.uk](mailto:patientvoice@blf.org.uk).

## Providing information and support

### Booklets and leaflets

We revised our patient information to produce our 'Living with pulmonary fibrosis' booklet suitable for anyone with any type of pulmonary fibrosis, while updating our 'IPF' leaflet.

*"The 'Living with pulmonary fibrosis' booklet is excellent by the way and I had a chance to read it thoroughly. I only wish my wife and I had had it sooner, as we may have been able to take better decisions about our lifestyle." Pulmonary fibrosis carer.*

Our new *Living with pulmonary fibrosis* booklet now has the first ever clear, lay explanation of the difference between pulmonary fibrosis and ILD. It also contains clear information about the classification of different types of ILD. Both of these are incredibly important as feedback from patients suggested that there was considerable confusion around diagnosis. There is also a brand new section on ways to help your breathing, designed specifically with pulmonary fibrosis patients in mind. As well as this we've included two new patient stories. In 2016 we distributed almost 20,000 booklets - this includes both the new pulmonary fibrosis booklet and the former 'IPF and other interstitial lung diseases' booklet.

Additionally we updated our new IPF leaflet which now has clearer advice and information. We distributed over 25,000 IPF leaflets in 2016.

We also continued piloting our IPF personal organiser. This pilot is now finished with excellent feedback from the patients involved. Thank you to everyone who took part. We'll now be developing the organiser into a downloadable online resource to help patients better manage their condition.

*"The organiser is an excellent way for the newly diagnosed to chart their own progress and centre on what treatments are most effective." Pilot participant.*

### Our health information is accredited by the Information Standard

The Information Standard (IS) is a certification scheme, run by NHS England, that assesses the processes an organisation follows to make sure it produces high quality health and social care information for the public.

All our health information is reviewed regularly by both health care professionals and patients to make sure we have easy to understand information that the public can trust.

### Online resources

Along with the launch of our new pulmonary fibrosis booklet, we launched a new web hub focusing on pulmonary fibrosis. We hope this will reach and support even more people. In the first three months since its launch the hub has had almost 50,000 visits. We also updated our online information on pulmonary fibrosis services around the UK - an incredibly valuable resource that explains the differences in pulmonary fibrosis health care between nations and highlights key ILD centres in the UK.

We continue to have information on IPF on our website, and throughout 2016 we received 252,000 visits, in line with the previous year. We included a new online section on questions to ask your health care professional. We also updated our comprehensive summary explaining IPF research, which helps patients and their families find reliable, easy to understand information about IPF research.



Newly launched on our website at the end of 2016 was information on children's ILDs. Clinically children's ILDs are very different from adult ILDs, so needed a separate resource.

We continue to publish blogs (short stories) that share patient experiences. These blogs can be a valuable resource for people going through similar experiences. For instance in December 2016 we shared on Facebook Christine's experience of how pulmonary fibrosis had left her with no independence. This reached 14,000 people, with many people leaving comments or sharing with others.

*"[Christine's experience] rings so true. I'm lucky enough to still work but I do feel my independence is being lost every day. I've remained stable for 5 years but feel I'm deteriorating at present. Everything feels harder at the moment." Facebook comment.*

Blogs we've published in previous years also continue to be extremely popular and help patients navigate their journey after diagnosis. David's blog on his experiences near the end of his life is now ranked at the top of Google search results internationally when people enquire about end of life with IPF.

Our blog *9 things people with lung disease want you to know*, written by Ann who has IPF, continues to be extremely popular and strikes a chord with many people. This is a great example of how more general information about lung disease can be used to help family members understand more about the condition.

*“Thank you for sharing this article [Ann’s blog] as my mum has pulmonary fibrosis and has become very poorly very quickly and I have not known what is the right thing to do. I feel so helpless that I can’t make her ok. However I feel now that I can understand a little more what she is going through and how I can maybe help make things a little easier for her.” Facebook comment.*

#### **Information events**

This year we extended our well received IPF Meet the Expert events to anyone with pulmonary fibrosis. We held our first ever event in North Wales, with all 54 delegates rating the event as good or excellent. Most delegates felt that the event had helped them learn more, feel more confident, and helped them to find out where to get further support.

We also held our first event in London in partnership with the Royal Society of Medicine *Medicine and Me* programme called *Living with pulmonary fibrosis*. In conjunction with the event we published an article in The Lancet Respiratory Medicine journal explaining IPF, giving patient stories and highlighted the importance of communication between those living with IPF and their clinical teams.

The *Medicine and Me* event had 148 delegates with an approximate split of 70% patients, carers and family members and 30% health care professionals. The delegates found the meeting very relevant - they rated it 4.57 out of 5. All the presentations were filmed and put online. This has enabled patients and families who were not able to attend one of our face to face meetings to find out more about pulmonary fibrosis.

*“Following on from the great conference in London yesterday the Brooke’s family is now totally committed to being IPF Warriors!” Facebook comment.*

*“WOW. I’ve watched these videos for most of the afternoon and they are brilliant and very encouraging and reassuring! They have come just in time for my appointments and investigations at the [hospital] next week. I feel so much better informed and know even more questions to ask now! A BIG THANK YOU for sharing them.” Facebook comment.*

## Support groups

The number of pulmonary fibrosis support groups around the UK continues to grow with around 40 in the UK. We help to support these groups in a variety of ways including providing a bursary when setting-up, expert advice and giving presentations on the support that is available. We also connect groups with their local Breathe Easy support groups. Breathe Easy support groups are for anyone with any lung condition, and we have many members who have pulmonary fibrosis. There are over 230 Breathe Easy groups around the UK.

In Spring 2016 we held two pulmonary fibrosis support group networking conferences - in Swindon and Manchester. These were funded by Boehringer Ingelheim and Roche Products Ltd.

Representatives from 21 different pulmonary fibrosis support groups across the UK attended, reaching 64% of local pulmonary fibrosis support groups in the UK at the time. The conferences gave representatives a chance to network and learn from each other, take useful information back to their support groups and discuss the future of a UK wide support group network. The conferences were rated as excellent (58%) or very good (42%). We're planning to continue to keep support groups in contact with each other.

*“It was a very enjoyable and stimulating day. With your help, patients can do much to help and support each other.” Conference feedback.*

## Helpline and Health Unlocked

Our helpline is there for anyone who wants to get in touch and talk about any problems they may be having, whether they are medical, emotional or financial. We have fully qualified nurses and expert advisers who are able to help. Around one in ten calls to our helpline continue to be related to pulmonary fibrosis. Our online web community - Health Unlocked - also provides valuable support for those affected by pulmonary fibrosis.



## Raising awareness and influencing

### World IPF week 2017

For World IPF week this year our main theme was research and hope. We announced we'd be spending £300,000 on pulmonary fibrosis research in the next year and launched our new updated patient information.

We spoke about this funding through a radio day, where we had a medical expert available to speak to radio stations around the country. We also promoted local patient stories to radio stations and newspapers. As a result we got over 50 articles in the press, with excellent coverage in each of the nations.

A highlight shortly after IPF week was our article in the Mail Online, which was shared over 2,300 times directly from the webpage, and also had 356 shares, with 493 likes, when we published the story on Facebook. Our research blog was also extremely well received. This was promoted through a sponsored Facebook post which reached 48,446 people and had 2,581 reactions.

*"It's been a very interesting week. A little worrying as well though, as I've been approached by several people in my local area who aren't getting the support or information regarding treatment or therapy to help relieve symptoms. I think that the media campaign has been very successful, was much needed, but needs to be continued. Fight today for more tomorrows." Local patient media representative.*

We raised awareness of IPF to health care professionals through five different media articles including the Hippocratic Post and the British Journal of General Practice Nurses. We promoted IPF Week and a Twitter chat through our health care professional newsletter. The Twitter chat focused on breathlessness and IPF, and was supported by the British Journal of General Practice Nursing and the ILD-Interdisciplinary Network. The European Idiopathic Pulmonary Fibrosis Federation, the Association of Respiratory Nurse Specialists, and the Association of Chartered Physiotherapists in Respiratory Care also took part.

Patient stories, experiences and support are absolutely vital to make IPF Week a success. We used two patient videos to tell people about living with IPF. The videos were viewed by almost 10,000 people. Our Facebook posts also generated lots of comments with people telling their own story and offering to help. We featured Philip and his wife who walked 186 miles in support of their friend Steve when he told them he had pulmonary fibrosis.



*Behind the scenes: Preparing packs for IPF week and promoting our health care professional chat on Twitter*

A graphic for a Twitter chat event. At the top, it says 'Brit Lung Foundation @lunguk'. Below that, it reads 'HCPs talk IPF and breathlessness in Twitter chat hosted by us, @gpnreport & @ild\_inn on 21 Sep. Join using #knowIPF'. The main part of the graphic is a blue box with white text that says 'Join us for our twitter chat Wed 21 Sep at 8pm #knowIPF'. To the right of this text is a red balloon with the 'British Lung Foundation' logo. Below the main text is a list of four discussion topics:

- How do you support patients' oxygen needs in general practice and the community?
- What is the difference between oxygen therapy for COPD and IPF?
- How useful is long-term oxygen therapy (LTOT) for your IPF patients?
- Is it beneficial for patients to monitor their own oxygen saturation levels?

At the bottom, it says 'Supported by the British Journal of General Practice Nursing and ILD Interdisciplinary Network'.

Breathe Easy and pulmonary fibrosis support groups also raised awareness during the week at their local hospitals, GP surgeries and fundraising events, and we provided IPF week information packs to support their different activities. We encouraged all our supporters to take part in IPF Week in a supporter email sent out to over 40,000 people, with about a fifth of people opening it.

## Media

We continued to ensure that pulmonary fibrosis had a strong profile in the media, with 115 pieces in the regional and national media with a potential media reach of 180 million. Highlights were articles in the Telegraph, the Daily Mail, the Huffington Post and the Scottish Herald, while we appeared on ITV Wales and STV. In the medical press we had eight articles including Nursing in Practice, Management in Practice, Medical News Today and The Lancet Respiratory Medicine.

We had over 26,000 followers on the BLF Facebook page and over 12,000 followers on Twitter. We posted regular items about pulmonary fibrosis on both these accounts on new research, personal stories, campaigns and events. We also communicated with regular posts on other pulmonary fibrosis Facebook groups.

### ILD care pathway roundtable

We held an ILD care pathway roundtable in November 2016. In total 30 experts from across the UK attended representing specialist ILD services, general practice, patient and family members, commissioners and other pulmonary fibrosis charities.

We examined and explored the care that people living with an ILD are currently receiving across the UK. We discussed what a best practice care pathway should look like and discussed what key principles of care should underpin these pathways. Recommendations from the roundtable will be used to inform a policy report that will be published in 2017. We'll use this to further influence decision-makers locally and nationally and improve care for people living with ILD around the country.



*Behind the scenes: Attendees at our ILD care pathway round table*

### Across the nations

We continue our work representing the patient voice across the nations. The BLF Wales team represented the patient perspective in the development of the new service proposal for Wales and campaigned for implementation. Out of this a new virtual service for treating and diagnosing people with ILD was funded by the Welsh Government in April 2016.

For a number of years we were concerned that only people from Cardiff had access to a multidisciplinary team and were receiving a service in keeping with the NICE guidelines. While consultants in other health boards were able to prescribe drugs, they didn't have access to the range of professionals needed to make an accurate diagnosis or the specialist nursing support to help manage the condition going forward. The new virtual network allows consultants from across Wales to access specialist clinical support from elsewhere to make an accurate diagnosis. In the first six months of the new service there were 164 referrals with an average wait of just three weeks.

In Scotland we continue to be a member of the Scottish National Advisory Group for ILDs. We are ensuring we have strong and growing relationships with health care professionals across Scotland through attending relevant meetings and conferences, facilitating workshops, and engaging and being a member of the newly formed ILD Scottish Practitioners Group. The Scottish team have also increased the profile of pulmonary fibrosis in the press through patient stories and ensuring the voice of the patient is heard.

In Northern Ireland we were invited to present to an ILD workshop bringing clinical staff together with commissioners in the Public Health Agency and Health and Social Care Board. The aim of the workshop was to look at the current Northern Ireland ILD service delivery model, the challenges that currently exist, and to consider a range of options to improve services. Our Head of Scotland and Northern Ireland co-presented with a family member who was affected by pulmonary fibrosis. This was incredibly well received by the health care professional and commissioning delegates involved. We are now on the working group that's considering the future of ILD services in Northern Ireland.

In England we represent the patient voice on the NHS England Specialised Respiratory Clinical Reference Group, which writes the specifications for ILD services. In doing this we responded to several consultations by NHS England and successfully argued to protect patient and public voice roles and improve transparency in Clinical Reference Groups. Locally we have attended specialist ILD commissioning events and meetings with ILD leads to help provide patient and BLF perspective for establishing regional networks and clinical pathways.

### **Linking with European organisations**

In 2016 we became a founding member of the European Idiopathic Pulmonary Fibrosis Foundation (EU-IPFF). We met with other European IPF organisations to plan how to raise the profile of IPF across Europe and improve standards of patient care. As part of this we supported a European IPF charter calling for action and we attended an event at the European Union parliament in Brussels to show our support for the charter.

### Supporting health care professionals

Patients' experiences of care can still vary widely around the country. We regularly hold health care professional study days across the UK, with over 400 delegates a year. The majority of these study days have a session focusing on pulmonary fibrosis to help increase understanding and knowledge. We also help support local study days with patient information leaflets and booklets.

This year we held an event in conjunction with the Royal Society of Medicine called Living with pulmonary fibrosis that was aimed at health care professionals and patients. We also had a stall at the inaugural ILD Interdisciplinary Network (ILD-INN) conference in the autumn and our Chief Operating Officer spoke at the event.

*"I just wanted to say thank you for all the BLF stuff you sent. I did 40 goodie bags... We had 37 nurses attend and our speakers. The Velcro cards went down really well and nobody had seen anything like it before" Health care professional.*

*"[The consultant] asked if it was OK for two med. students to sit in... I offered for them to examine me too if she thought it appropriate, and she was keen! They were 4th years, and both diagnosed me correctly mentioning the "velco" sound! Result! I hope the awareness is growing among young frontline professionals." Pulmonary fibrosis patient.*

## Research

### New IPF data 'Battle for breath'

We published new comprehensive data on IPF in April 2016. Our special report, called *Battle for breath*, found that 32,500 people are living with IPF in the UK. The report also published data on pneumoconiosis and sarcoidosis.

We found the prevalence rate for IPF to be about 50 per 100,000. This is more than double NICE's estimate of 15-25 per 100,000 (NICE 2015).

*"These figures show more clearly than ever that tackling IPF needs to be made a priority." Dr Penny Woods, CEO, BLF*

We also found out more about the impact of hospital services. There are nearly 9,000 admissions a year for IPF. There are also 86,000 hospital bed days per year accounted for by IPF. Although the total impact on health services is relatively low, the impact for each person living with pulmonary fibrosis is higher than for most other lung diseases. IPF accounts for around 1.4% of all hospital bed days and 1.3% of all admissions due to lung disease. This is despite its having been diagnosed in less than 0.25% of people who have had a diagnosis of lung disease.

To coincide with the launch of the new data we worked with the Daily Telegraph on an exclusive article outlining the key data and recommendations from the report. Our key recommendation is that policy-makers should set up lung disease taskforces in England and Scotland. Northern Ireland and Wales already have taskforces or plans in place. We can't leave anyone else behind. This will help improve the quality of care for pulmonary fibrosis.



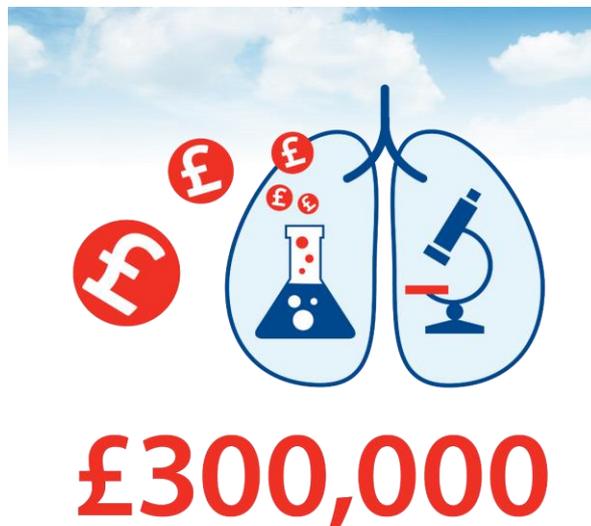
*Behind the scenes: Campaigning for greater awareness*

### Promoting the BTS ILD registry

We continue to work in partnership with the British Thoracic Society (BTS) to promote the BTS ILD Registry for IPF and sarcoidosis. The aim of the ILD Registry is to provide a means of reviewing nationwide data for these comparatively rare diseases; enabling a greater understanding of their epidemiology and ultimately helping to improve diagnosis and care for patients.

At the end of November 2016 there were 47 NHS hospitals actively participating in the registry and 29 others in the approval process. On the database there were 1,055 IPF patient records and 286 sarcoidosis records. You can find out more and read the initial findings at [brit-thoracic.org.uk/standards-of-care/lung-disease-registries/bts-ild-registry](http://brit-thoracic.org.uk/standards-of-care/lung-disease-registries/bts-ild-registry).

### Our commitment to research



We made a commitment during IPF Week 2016 to fund an extra £300,000 of ILD research by the end of 2017.

## Research studies awarded in 2015-16

We continue to fund research into ILD, including IPF, and we've awarded over £2 million to ILD research so far. In our financial year 2015-16<sup>3</sup> we awarded an additional £108,000 towards ILD research. We aim to drive research in areas where we feel we can make a real difference to patient outcomes. We have a research committee made up of patient and health care professional representatives who help decide what research we fund.

<p><b>Singing for breathing in idiopathic pulmonary fibrosis</b>  <i>Lead:</i> Anne-Marie Russell          Royal Brompton Hospital  <i>Amount:</i> £10,000  <i>Duration:</i> 10 months</p>	<p>Evaluating the effectiveness of singing for breathing in patients diagnosed with a restrictive lung condition - IPF or NSIP. 12 group workshops will be facilitated over a period of six months. Findings will be used to inform a research proposal and if successful an application for a larger research grant.</p>
<p><b>Molecular profiling of the pulmonary epithelium in IPF (lab. study)</b>  <i>Lead:</i> Prof. Rachel Chambers          University College London  <i>Amount:</i> £24,726  <i>Duration:</i> 6 months</p>	<p>Understanding disease mechanisms and identifying new drug targets while developing new techniques to study free circulating DNA in alveolar epithelial cells.</p>
<p><b>UK collaboration to study inflammatory and fibrosing lung disease in people with immune deficiency</b>  <i>Lead:</i> Dr John Hurst          University College London  <i>Amount:</i> £24,672  <i>Duration:</i> 24 months</p>	<p>Creating a UK network of clinicians and patients to develop good practice guidelines on granulomatous-lymphocytic interstitial lung disease (GLILD). As well as creating a biobank, developing patient information and encouraging further research.</p>
<p><b>A human model of lung fibrosis (lab. study)</b>  <i>Lead:</i> Dr Katy Roach          University of Leicester  <i>Amount:</i> £24,072  <i>Duration:</i> 12 months</p>	<p>Ensuring that a model of a human lung with IPF is suitable and can be used to study and develop effective treatments for IPF.</p>
<p><b>Immune cell regulation of fibrotic lung disease (lab. study)</b>  <i>Lead:</i> Dr Robin McAnulty          University College London  <i>Amount:</i> £25,000  <i>Duration:</i> 18 months</p>	<p>Inhibiting a cell signalling molecule (STAT3) to see if this blocks a type of white blood cell important in immune protection (B-cells) and examining the effect on lung fibrosis.</p>

<sup>3</sup> Our research funding year aligns with our financial year from July 2015 to June 2016

### Initial research studies awarded in 2016-17

We are part way through our funding year for 2016-17<sup>4</sup> and have funded further ILD research studies. We've made a commitment during IPF Week 2016 to fund an extra £300,000 of ILD research by the end of 2017.

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**Dissecting the WISP signalling network in idiopathic pulmonary fibrosis (lab. study)**

*Lead:* Prof. Donna Davies

University of Southampton

*Amount:* £40,000 with additional funding from Wessex Medical Research

*Duration:* 4 years

There is a clear unmet clinical need to understand mechanisms of IPF in order to improve therapy options. This research will investigate the role of WNT-inducible signalling protein-1 (WISP-1), a profibrotic mediator strongly implicated in the development of IPF pathogenesis. This research is specifically designed to provide a wide ranging training programme for a PhD studentship, bringing a new investigator into ILD research.

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**Targeting DNA methylation as a potential treatment for lung fibrosis (lab.study)**

*Lead:* Prof. Robin McAnulty

University College London

*Amount:* £25,000

*Duration:* 36 months

The researchers have got novel data suggesting that a large number of genes are regulated differently in fibrotic lung fibroblasts. The data suggests that these genes are all regulated by a similar mechanism, involving a chemical modification (methylation) of each gene's DNA, leading to altered production of their proteins. Changes in methylation can be modulated with drugs currently used to treat some cancers. In the proposed studies they will treat human fibrotic lung fibroblasts with clinically available drugs to look at their potential therapeutic effects on genes and cellular functions associated with the development of lung fibrosis. If this research is successful, repurposing of drugs currently approved for use in other diseases could lead to more rapid progress to clinical trials.

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<sup>4</sup> Our research funding year aligns with our financial year from July 2016 to June 2017

## Marie's story: Falling from 13,000 feet to fight IPF

I met Les when I was 15. In 1966, aged 19, we were married. We were very happy together. Then late in 2008 he developed this annoying cough, so we went to the doctor. At first, we thought it was just a chest infection. But then in March 2009 a diagnosis of pulmonary fibrosis was given. By August, Les was on oxygen. A few months later in November, he died. It was just eight months after his diagnosis.



Les was everything to me. Losing him was so hard. Pulmonary fibrosis is such an insidious, shockingly cruel condition. That's why I decided to start fundraising. If the money can go to research which can help other people, then it's worthwhile.

### Fundraising in memory of Les

The year after Les died, I did the Midland Lung Run. I can't really run but I did it! Now twice a year I do a coffee day where I sell cakes, any plants I've grown, and crafty things I've made.

I'd never have dreamed of doing a skydive. But this year when the BLF newsletter came through with different events, I saw they were having a skydiving day in May. That would have been Les's 70th birthday, and 7 years since he died. I decided I would do it, and try to raise £700!

People kept asking me, "aren't you afraid?" But I wasn't. Sometimes in life, I think we have to think very carefully about what we plan to do - but sometimes I think we just have to say, you know what? I'm just going to do it! So that's what I did.

### The big day

The first plane went up at 10am. I was watching from the ground. Gosh, I hadn't realised how high up it was going to be! 20 minutes later it was just this tiny little thing, way high up in the sky - 13,000 feet. At this point I thought, "oh my gosh, what am I doing?" At 68, I was the oldest person there by far. But then it was time for me to go and get my flying suit on - and up I went!

It was just beautiful, and incredibly exhilarating. We freefell for 45 seconds, then suddenly I heard a flapping sound and my parachute went out and everything went so quiet. We just drifted down. It was amazing, honestly. It's all worth it.

People ask me what I think Les would have said. I think he would have told me I was bloody mad! But proud of me, like he always was. He was such an incredibly funny, lovely man. This condition has no respect for anything or anyone. It was so awful to watch him struggle so much.

I set out to raise £700, but I've raised much more than that - at the last count it was over £2000! I know that money I've raised can help other people, and it makes it all so worthwhile.

## Summary of our successes, 2013-2014

Further information about the first year of the project can be found in *Providing better support and awareness for people with idiopathic pulmonary fibrosis (IPF) Year 1: IPF project report*.

### Getting started

- *IPF Patient Charter* with ten key calls to action after a wide ranging consultation.

### Providing information and support

- The first ever IPF information pack produced, with over 6,000 packs ordered in the first six months.
- 'Meet the Expert' events for people with IPF and their families, with over 77% of those attending telling us that their understanding of IPF had improved.
- Seven new pulmonary fibrosis support groups launched around the UK so far, providing a bursary and expertise.
- Over 120,000 visits to the IPF information on our website in one year, with a new IPF hub launched half way through the year.
- Over 16,000 visits to our IPF blogs.
- National media reach of over 14 million people during IPF week, and getting our supporters, celebrities and health care professionals involved.

### Influencing health care services and raising awareness

- Over 70 pieces on IPF into national and regional media, with a total media reach of over 40 million people.
- Mapping the locations of ILD services and pulmonary fibrosis support groups around the UK and making this information available online.
- Strengthening relationships for the continued development of ILD services and supporting policy development around the country in Scotland, Wales, Northern Ireland and England.
- Over 300 of our supporters, including over 150 people with IPF and their carers giving us their views so we could feedback on NICE quality standards.
- Holding our first Westminster parliamentary event on IPF giving MPs a chance to speak to people living with IPF and their carers; as a result over ten parliamentary questions were asked.
- Providing training for nurses and affiliated health care professionals on IPF and ILD, with delegates telling us that as a result of the day they are now more knowledgeable about the diagnosis, treatment and prevalence of IPF/ILD.

## Summary of our successes, 2014-2015

Further information about the second year of the project can be found in *Showing how we care about idiopathic pulmonary fibrosis: Increasing support and awareness Year 2: IPF project report*.

### Providing information and support

- We had over 250,000 visits to our online IPF hub.
- There were over 13,000 IPF information packs ordered in the first year since launch, from Shetland to the Channel Islands, with excellent feedback from patients.
- This year over 450 people living with IPF and their families attended 'IPF Meet the Expert' events, with 97% telling us they had learnt more and 83% telling us they now feel more confident living with IPF.
- So far we have helped launch 13 new pulmonary fibrosis support groups around the UK by providing a bursary and expertise, including the first ever pulmonary fibrosis support group in Northern Ireland.
- Our blog on *IPF the final stages* by David was viewed over 17,000 times in the year.
- Our Helpline continued to support people living with IPF and their families, with one in ten calls being IPF-related.

### Influencing health care services and raising awareness

- We reached over 50% of MPs leading up to the launch of our patient experience report, with over 50 parliamentarians and policy makers attending our event about IPF in Westminster.
- The success continued with the launch of our Welsh patient experience report at the Welsh National Assembly for Wales, with the Deputy Minister for Health giving a speech on the importance of pulmonary fibrosis services.
- During IPF week over 25,000 people saw our Facebook posts at the highest point during the week, compared to 5,000 on a normal week.
- We generated over 140 pieces in regional and national media with a potential media reach of over 114 million.
- Our study days for health care professionals covered ILDs and reached over 500 people.

### Research

- We encouraged patient-centred research by collaborating with leading researchers on a journal article and supporting the recruitment of participants into a study for patient reported outcome measures.
- In our financial year 2014-15 we awarded £270,000 towards ILD research. We've awarded over £2 million to ILD research so far.

## Looking forward to 2017 and beyond

We are continuing to build on our work on pulmonary fibrosis and are committed to supporting people living with pulmonary fibrosis, their families and carers. We will continue to call for action from policy makers, politicians and health care professionals. In 2017 our activity will include producing a policy report calling for improved services together with a parliamentary event, we'll be launching an online personal organiser and we'll be holding further patient events. We could not do all that we do without continuing input and fundraising from all our supporters. So thank you to everyone who has helped.

## Resources

The BLF has lots of information about pulmonary fibrosis and living with a lung condition. You can access this in online and print.

You might find these useful:

- *Living with pulmonary fibrosis*
- *Idiopathic pulmonary fibrosis*
- *Looking after someone with a lung condition*
- *Coping with the final stages of chronic lung disease*
- *Breathlessness*
- *Oxygen treatment*
- *Living with a lung condition*
- *Going on holiday with a lung condition*

You can order booklets and leaflets at [blf.org.uk/publications](http://blf.org.uk/publications) or by calling 03000 030 555.

Online you can find lots of information about pulmonary fibrosis at [blf.org.uk/pf](http://blf.org.uk/pf). Online you can also find information about welfare benefits. Looking after your lungs in hot weather, singing for lung health, air pollution and more.

Whether you have a lung condition or care for someone who does, we're here to help. You can get in touch with our helpline at 03000 030 555.

## Acknowledgements

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Thank you to all of our supporters who have helped raise funds for our research and other work to tackle IPF. We couldn't have undertaken this activity without you. Particular thanks go to Richard and Philippa Mintz, and Laurance and Jacki Racke who have all made significant contributions towards our ongoing research work.

We really appreciate the help and views from our supporters living with pulmonary fibrosis, their family and carers who have taken part in our media activity, patient events and focus groups. A special thanks to members of our Patient Think Tank who have given us invaluable advice.

## Supporting us

### Corporate partnerships

If you or your company would like to find out about becoming a partner or supporter of our pulmonary fibrosis work, please contact our corporate partnerships team.

Email: [corporate@blf.org.uk](mailto:corporate@blf.org.uk)

### Patients, carers and family members

If you have pulmonary fibrosis or know someone who does and would like to help us continue to raise awareness of the condition, there are lots of different ways you can get involved. You can tell us your story, join a focus group or fundraise for pulmonary fibrosis research and support.

Email: [patientvoice@blf.org.uk](mailto:patientvoice@blf.org.uk)

### Health care professionals

If you are a health care professional and would like more information on our pulmonary fibrosis work, please contact our stakeholder engagement team. You can also become a BLF Professional and support our work, or you can fundraise for us.

Email: [HCP@blf.org.uk](mailto:HCP@blf.org.uk)

*“Thank you all, for helping us provide support, increase awareness, and fund more research. This year I’ve heard amazing stories from those who’ve received the best of care. Sadly, there have been some equally impactful stories of the difficulties some people have faced. We need to change this. We’ll make sure that everyone living with pulmonary fibrosis has a voice.” Ruth Sabella, project manager, BLF*

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