Providing better support and awareness for people with idiopathic pulmonary fibrosis (IPF)

Year 1: IPF project report

November 2013 – October 2014

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Foreword

Respiratory diseases are among the leading causes of death worldwide. In the UK, they affect one in five people, and are the third most common reason for death.

Many people will have heard of asthma, bronchitis or lung cancer but there are other, less well-known respiratory conditions that are also in urgent need of attention.

Idiopathic pulmonary fibrosis (IPF) is a chronic, progressive disease where the lungs become scarred over time. Despite it being a truly devastating disease, most people have never heard of it. I'm often told by people affected by IPF that their initial reaction upon getting their diagnosis is one of relief it isn't cancer.

However, IPF can be every bit as terrible as cancer, and often worse. Almost half of those diagnosed are likely to die within just three years from diagnosis. The number of people with IPF in the UK is increasing by around 5% a year; today it kills more people each year than leukaemia.

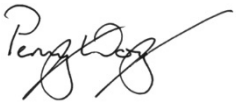
All this and we still don't know what causes it. There are limited treatments and no cure.

We spoke to patients, carers and healthcare professionals about the impact IPF has. From this we developed 10 key calls to action in our Patient Charter, and have focused our work around these key issues.

During the first year of our IPF programme the British Lung Foundation has been working with people with IPF and health care professionals to develop and disseminate the most up-to-date information for patients and clinicians, raise awareness through the media and provide health care professional training. The BLF also continues to fund vital research to improve our knowledge of IPF and the development of appropriate treatments and care. We've made a difference, however there is still so much to do.

Our focus for 2015 and beyond will be to continue to improve the lives of everyone living with IPF. We are calling for access to seamless, well-integrated health and social care services. We want to make sure that every person with IPF has access to high quality information and support at diagnosis and beyond.

Together with our supporters we will continue to lead the fight against IPF.



Penny Woods

Chief Executive, British Lung Foundation

Executive summary

This report examines our first year of activity and action in our IPF project. In 2013 the British Lung Foundation (BLF) decided to make interstitial lung disease (ILD), with a focus on idiopathic pulmonary fibrosis (IPF), a priority. There are around 15,000 people with IPF in the UK at any one time and every year around 5,000 people will be diagnosed with IPF. Unfortunately 50% of people will die within three years of diagnosis. However, individual survival is difficult to predict and some people will live a lot longer than this. There is no cure, yet, for IPF. People with IPF and their carers often feel isolated and experience high levels of stress and depression.

As a first step to tackling these problems we launched an IPF Patient Charter with ten key calls to action after consulting with health care professionals, researchers, people living with IPF, carers, family members and campaigners. In November 2013 we started a two year funded project based on the IPF patient charter, to build support for people with IPF and their families and influence health care services. In the first year of the project we have achieved a tremendous amount, thanks to the help of all our supporters.

During the last week in September, organisations from across the globe came together for World IPF Week. At the BLF we generated a media reach of over 14 million people in just seven days. Incredibly, the number of views of our online IPF health information increased by more than 70% during IPF Week. This shows that as well as raising awareness of IPF to the general population, we also highlighted the information available to support people with IPF and their families.

However, our campaigning doesn't happen in just one week of the year. We lead the fight against IPF continuously. Our total media reach for 2014 was over 40 million people. We launched our new online IPF hub in May, bringing updated and award-winning IPF health information, as well as accounts of living with IPF, to an online audience. And in just one year, we had over 120,000 visits to our IPF website information, blog stories and shop products.

Our resources cover a wide range of media. In addition to our online information, we launched the first ever IPF information pack, with over 6,000 packs ordered in the first 6 months. We also held a series of 'Meet the Expert' events for people with IPF and their families around the UK. 77% of the people who attended told us their understanding of IPF had improved as a result of the event. We supported seven pulmonary fibrosis support groups with a small bursary and expertise and spoke at many more events and groups.

Influencing health care services and raising awareness is a crucial part of our work. In 2014, we held our first ever Westminster parliamentary event on IPF and supported the continued development of ILD services and policy around the country in Scotland, Wales, Northern Ireland and England. We also engaged with over 300 of our supporters, including over 150 people with IPF and their carers, to feedback on NICE quality standards. We supported health care professionals by holding several study days throughout the year, including one session focusing on IPF, and piloted ILD shadowing days with two nurses from Northern Ireland.

Working together around the UK we can make a difference in the fight against IPF. Our plans for next year include carrying out a large scale patient experience survey, building online IPF resources for health care professionals, and launching the first ever IPF campaign report in parliament. Ensuring we continue to have strong relationships with people with IPF and their families, health care professionals, politicians and policy makers across the whole of the UK will be central to this.

Getting started

Background

In 2013 the British Lung Foundation (BLF) decided to focus on five key priorities, while ensuring that we continued to support everyone with a lung disease. One of these priorities was interstitial lung disease (ILD), with an initial focus on idiopathic pulmonary fibrosis (IPF).

There are around 15,000 people with IPF in the UK at any one time[1]. Every year in the UK around 5,000 people will be diagnosed with IPF, and every year around 5,000 people will die from IPF[1]. This is comparable to far better known conditions such as leukaemia[1].

Almost 50% of people will die within three years of diagnosis. However, individual survival is difficult to predict and some people will live a lot longer than this. About 20% of people live for more than 5 years[2]. The number of people with IPF is increasing each year by around 5%, with no clear reason for this increase[1]

Alongside the debilitating physical symptoms of IPF, patients and their carers often feel isolated, experiencing high levels of stress and depression. This in turn may make it difficult for them to manage their condition[3,4,5]. Specialist health services may be difficult to access and the condition itself may make it difficult to meet others in the same situation.

Unfortunately, there is no cure yet for IPF. For a very few people, having a lung transplant might be an option. There is currently one drug (pirfenidone), licensed for use by the NHS in 2013, that slows down the development of scar tissue in the lungs of people with IPF. A second (nintedanib) has recently shown similar effects and is likely to be approved for use in the NHS before the end of 2015.

What is IPF?

Idiopathic pulmonary fibrosis (IPF) is a progressive condition where scar tissue builds up in the lungs, making them thick and hard. People with IPF can feel breathless from simple everyday activities. Coughing is another common symptom.

Idiopathic – cause is unknown

Pulmonary – affects the lungs

Fibrosis – scar formation

"Watching him suffer, and being utterly helpless to alleviate his suffering, is indescribable, but the lack of support from the GP and assorted health professionals compounded our anxieties. The local hospice put us in touch with a charity who could help fill in a form for support for him, but when that charity realised he didn't have cancer, they said they couldn't help."
Carer for someone with IPF

Taking action

As a first step to take action, the BLF started by holding a roundtable in March 2013. Thirty people took part including health care professionals, researchers, people living with IPF, carers, family members and campaigners. From this meeting an IPF Patient Charter was developed with ten key calls to actions. See page 17 to read the charter.

In November 2013 an IPF project manager was appointed to lead a two year funded project. The activity in this project is funded by Boehringer Ingelheim and Intermune (which has now been merged into Roche Products Ltd). The companies have no influence over the activities taking place or the content of our information. We also continue to fund research into IPF, with a new research strategy for ILD developed in the last year, see page 18 for further details.

[1] Navaratnam et al., 2011, *Thorax*, 66, 462-467
[2] NICE., 2013, IPF: the diagnosis and management of suspected IPF
[3] Bajwah et al., 2013, *Palliative Medicine*, 0, 1-8
[4] Akhtar et al., 2013, *Chronic Respiratory Disease*, 10, 127-133
[5] Belkin et al., 2014, *BMJ Open Respiratory Research*, 1, 1-7

Project aims

The aims, objectives and outcomes for the project were developed to reflect the ten key calls to action in the IPF Patient Charter. Project activity was categorised to reflect the two main objectives of the project.

Aim

To enable the BLF to take a pro-active approach towards developing a campaign, communications and support programme for IPF.

Objectives

- To ensure that people with IPF, their family and carers have the information and support they need to understand their illness, make decisions and make the most of their lives.
- To influence and shape NHS and other services to ensure they are accessible, integrated, appropriate and evidence based.

Outcomes

- Improved information and support for IPF patients, their families and carers
- Increased awareness of IPF and its symptoms
- Better patient experience for people with IPF along the patient pathway
- Improved timely referral at primary care level for diagnosis
- Progress towards the full implementation of the NICE guidelines for IPF

Year 1 plans

Providing information and support

- Develop IPF information packs
- Run a series of IPF 'Meet the Expert' patient events
- Help set-up pulmonary fibrosis support groups
- Build on our online resources for IPF
- Conduct research into the needs of people with IPF
- Use World IPF Week to raise awareness

Influencing health care services and raising awareness

- Influence commissioning and NICE guidelines
- Increase the profile of IPF through the media
- Raise awareness in parliament
- Map ILD services around the UK
- Develop a pilot for an IPF personal organiser
- Provide support for health care professionals

Key achievements

Summary of key achievements in 2013-2014

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 6 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.

Evaluating our activity

Providing information and support

Information packs

We developed the first ever IPF information pack to provide a high quality, comprehensive resource that is easy to hand out at diagnosis, and has space for local information to be added. The pack was launched in June 2014. Sample copies were sent to over 40 key health care professionals (including those at leading centres around the UK) and pulmonary fibrosis support groups. In conjunction with the launch an email was sent to over 2,000 contacts with an IPF connection.

Our press release was picked up by a number of organisations including the Primary Care Respiratory Society, the Nursing Standard, Medical News Today and the Mature Times. As a result of the promotional activity, visits to our IPF hub increased by 1,500 on day of launch (from around 500 visits a day to over 2,000).

In the first 6 months after the launch over 6,000 packs were ordered. A more comprehensive review of the information packs will take place in 2015. Initial feedback has been extremely positive.

Our IPF information pack

"Thank you so much for putting together the IPF information pack. When I was first diagnosed two years ago, I was given a photocopy of a typed (not even printed) A4 sheet for information and told to go and 'Google' for further information. I left the hospital feeling like I'd been handed a time bomb, I didn't know what to do or where to go for help. It's incredible how things have changed" *Person with IPF*

"We started using the packs on Monday and we thought they were really good. All our IPF patients took them. They really liked them as they are very handy. Putting all the information into a pack was a good idea, now we need to order more." *ILD Specialist Nurse*

Meet the Expert patient events

We held a series of 'Meet the Expert' events for people with idiopathic pulmonary fibrosis (IPF), their families and carers between September 2013 and March 2014. The aim of the events was to support the health and wellbeing of people with IPF, their families and carers. Just over 350 people with IPF, their families and carers attended the events, along with health care professionals. Locations were chosen to ensure a wide geographic spread across the UK.

The events were extremely well received by those who attended, with over 90% saying that the quality of the presenters and the content was good or excellent. The events ensured that people with IPF, their families and carers were better informed and had increased knowledge and confidence. 77% told us that their understanding had improved.

We have used the feedback from the series of events to inform our campaign for better services, which included deciding on our priorities from our IPF Patient Charter. In one area – Newcastle – holding a Meet the Expert event catalysed the formation of an IPF support group.

"Made me feel confident at dealing with my condition and what the future may hold." *Person with IPF*

"Helped me to understand the condition better - what should be happening in terms of the health care that my dad SHOULD be getting" *Carer for someone with IPF*

Support groups

We have so far supported seven pulmonary fibrosis support groups around the UK to help address the needs specific to people with pulmonary fibrosis and their families. These complement our network of over 230 Breathe Easy support groups which are for people with all lung disease. We help with practical aspects such as setting-up and developing the groups, providing a start-up bursary where needed and continuing ongoing support through BLF Direct (the BLF Helpline). An in-depth evaluation will be undertaken in Year 2 of the project.

Northern Ireland Breathe Easy group in their local town spreading the word about IPF

Our BLF Breathe Easy support groups have also been involved in raising awareness of IPF in their local areas. For example in Northern Ireland four Breathe Easy groups held meetings on IPF. A couple of Breathe Easy groups also set up a stand in their local community to promote awareness of IPF.

Jackie talks to us about setting up an IPF support group.

Jackie and Pat

I first noticed that my mum Pat was getting breathless when we were in holiday in Spain.

She was breathing more heavily than normal when we walked up the hill from the restaurant. I knew right away that it wasn't right, and that it just wasn't like her to struggle like that.

To be told she had idiopathic pulmonary fibrosis (IPF) was a real shock.

My uncle had died seven years earlier with something similar, and I'd assumed that it wouldn't happen again. I can't imagine how my mum felt – to be told there was no cure, no treatment and be left to deal with it.

I wanted to help and do whatever I could. I went to an event about IPF and spoke to someone who had set up a support group. We didn't have anything like that where we live in Derby – so I thought it would be a good idea to start one.

Martin, my husband, is very good at organising things, and he got the ball rolling. My mum's nurse, Mandy, also wanted to help, as well as a few other people with IPF that she knew.

We also contacted the British Lung Foundation who explained to us how support groups work, and what we needed to think about. They've been very supportive and their advice was invaluable in getting up and running quickly. Their IPF project manager, Ruth, also told us about World IPF Week, which raises awareness of the condition, so we targeted this week for our first area meeting.

To start with we held a small meeting so that we could get ideas about what we wanted from our support group. One of our main concerns was how we let people know about the group.

We have asked our local hospital's respiratory department to send out flyers. We also put information up around Derby in GP surgeries and community centres. I wasn't sure how it was going to work out but it was a start.

We held our first meeting yesterday and it was a big success. Ruth came along to talk about how the BLF can support us, and the BBC sent a reporter too. There was also lots of time for a cup of coffee and a chat – and we blew lots of bubbles, which is the theme of World IPF Week this year.

I'm looking forward to the next meeting and so is my mum.

Online resources

We created a new IPF hub on our website that was launched in May 2014. The hub includes updated and award-winning IPF health information and information about the latest research into IPF treatments. It also features opportunities for patients, carers and health care specialists to share their views on IPF care, information on support groups and services, and videos and written accounts of living with IPF. Since November 2013 there have been over 126,000 visits to our IPF website information, blog stories and shop products.

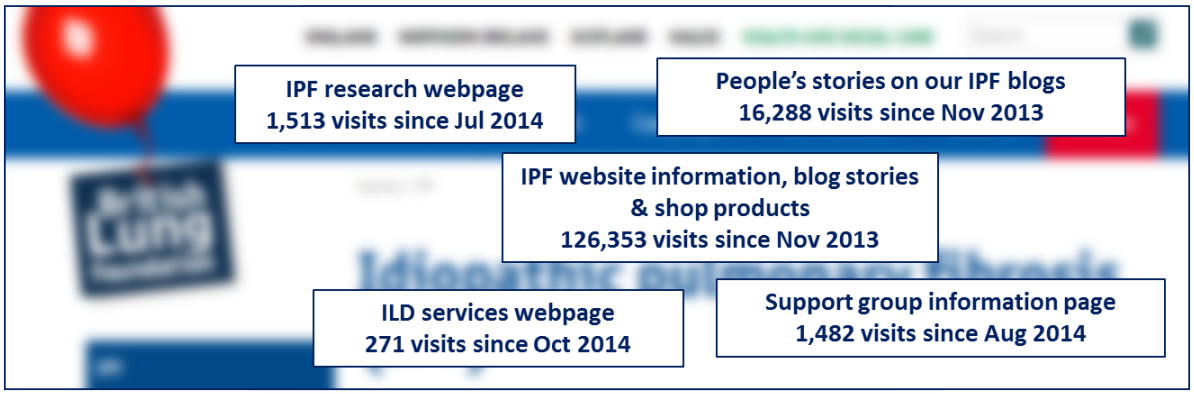
> "I have to say I am delighted with the increase in information being available to IPF sufferers. I lost my father just over three years ago to IPF at a time when very little was known or could be done, other than trial and error. Keep up the good work British Lung Foundation." *Facebook comment*

We asked an IPF researcher to write a patient-friendly overview to help people find out more about the current findings and knowledge about IPF. There have been over 15,000 visits to this page since its launch in July 2014.

> "You've answered questions doctors try to ignore whether they are afraid to tell you or simply don't know. My Dad has IPF and is coming to the end as its 5 years … I am my Dad's 24 hour carer and have tried in vain to find out what to expect in the coming months as Dad will stay at home…Thank You David you've made a difference." *Blog comment*

We also asked filmed an IPF online surgery with a leading ILD consultant explaining the new developments in treating IPF following the American Thoracic Society Conference in May 2014. This has been viewed over 1,000 times.

One of the more challenging stories we included in our online communications was a blog written by David Forder, who is entering the final stages of life with IPF. His story was read and shared by users across the world, with positive feedback on his open and honest approach to sharing his experiences.



Our IPF webpage in numbers

Researching the needs of people with IPF

In 2013 we collaborated with Boehringer Ingelheim to conduct some research into the needs of people with IPF. In-depth face-to-face interviews (of 90 to 120 minutes) with over 20 patients and carers in their homes were conducted by an independent market research agency. The discussions were analysed and key themes were identified. These included delays in diagnosis and referral to specialist care, the challenge of communicating the prognosis of IPF to patients, the benefits of peer support groups, and the importance of co-ordinated care. As a result of this research, we presented one poster at the European Respiratory Society International Congress 2014 and three posters at the British Thoracic Society Winter Meeting 2014.

World IPF Week

During World IPF Week organisations from across the globe come together to raise awareness. In 2014 this took place during the last week of September. Following the build-up of IPF activity over the last year of the IPF project, our reach and impact during World IPF Week was considerably higher than before. Of particular note was the BBC Online article by Dr Toby Maher that we placed to be published near the end of IPF week. This featured on the main BBC News health landing page and in just three days had been shared over 1,000 times. Our total national and local media reach for the week was over 14 million people.

We generated a real buzz around the week on social media. On Twitter there were almost 2,000 tweets throughout the week and around a quarter of these were retweets from our feed. On average we posted two Facebook messages a day to our 9,000 followers, and these were shared over 500 times and liked over 1,700 times. In addition we added posts to the pulmonary fibrosis Facebook pages.

> This year I'm supporting the BLF during World IPF Week – to help raise awareness about this nasty disease. Knowledge is power, and we desperately need research to find out more about IPF. That way, we can help everyone affected by IPF. If there's anything I can do to help people in my situation, then bring it on I say. *Person with IPF*

The health care community was extremely supportive. We held a Twitchat led by Nursing Times which received a really positive response and leading health care professionals wrote blogs for us.

We also held an information stand at the Primary Care Respiratory Society conference to raise awareness about early diagnosis.

Five celebrities helped us raise awareness on social media. Amanda Redman and Ray Winstone filmed an appeal video for us that we will continue to use in the future. Andrea Corr wrote a blog which generated over 5,000 page views, and we featured in West Ham United's match day programme.

Supporters blowing soap bubbles for IPF week

The press and social media activity drove people to our website with web page views of general IPF information up by 40 to 50% compared to the already strong numbers from the previous week. There was a 73% increase in the number of views of our online IPF health information.

Two pulmonary fibrosis support groups held their first meetings during IPF week, and we had local BBC TV coverage for both of these groups, as well as newspaper coverage. In addition to raising awareness of IPF, it also made local people affected by IPF aware of the support and help available. The support group in Derby had an increase in enquiries from people with IPF and family members following the press coverage. Our Breathe Easy groups also supported IPF week with 22 groups holding awareness raising or information stands.

Influencing health care services and raising awareness

Commissioning and NICE guidelines

We continue our work to influence health care services for people with IPF and their families. We sit on the Specialised Respiratory Clinical Reference Group. This group is looking at respiratory specialist services in England such as IPF. In Scotland we have supported the development and growth of the Scottish Interstitial Lung Disease Group, which provides a forum for discussion and sharing expertise for healthcare practitioners. Attendance at the group's meetings has doubled in the last year. In Wales we have played a key part in the formation of the Welsh Respiratory Delivery Plan that includes the management of ILDs through a multi-disciplinary team.

We submitted a detailed response to the National Institute for Health and Clinical Excellence (NICE) in relation to the development of an IPF 'Quality Standard'. For this we conducted a survey about key aspects of IPF care which 300 people answered. Over half of the responses were from people with IPF with the remaining respondents including family members, carers and health care professionals. We collated responses from the survey and used them as a basis of our feedback to the NICE advisory committee.

Media activity

This year we were able to significantly expand the profile of IPF in the media. We generated over 70 pieces in regional and national media, compared with 17 the previous year. Our media reach was over 40 million people. This included articles in the Scotsman, Wales Online, Sunday Post, the Guardian and Good Housekeeping magazine.

Joyce's story in Good Housekeeping

Through increasing our followers on the BLF Facebook page, becoming more engaged on ILD Facebook groups and by promoting a range of different posts from clinicians, patients, MPs and celebrities we continue to notice an increased interest in our activity on social media. This has allowed us to disseminate information about events, new research and personal stories with a good response. We have also increased our direct engagement with members of other relevant Facebook groups.

On Twitter, we have secured a strong health care professional following, including individual health care professionals who are leaders in the IPF field and major groups such as @WeNurses an online nurse community with 28,000 followers and @ARNS_UK which is part of the Association of Respiratory Nurse Specialists (ARNS).

Our online web community has also seen an increase in activity from pulmonary fibrosis patients and carers. This community provides valuable support for those affected by IPF.

> "I posted a few days ago about the hospital insisting my dad should attend outpatient appointments although he is in the end stage of IPF and terribly frail. Some members gave me good advice including to ring the BLF helpline which I did. The nurse was really informative and kind and she agreed there should be no need at this stage for him to be dragged into outpatients - the care should be coming to him now. She explained who I should ring and what to say, so we do have a plan now. Thank you everybody for your help and I definitely recommend ringing the helpline, they are excellent!" *Health Unlocked member*

Parliamentary awareness

Since November 2013 we have been building up our policy work on IPF. In March 2014, we surveyed MPs to find that that only 6% of MPs had talked about IPF with constituents or their colleagues. In July 2014 we held our first ever Westminster parliamentary event on IPF with a small number of people with IPF and their carers meeting MPs to tell their story. Backbenchers in both Houses were subsequently sent a briefing on what they could do to raise IPF awareness.

> "When I was told about the complex difficulties faced by IPF patients and their carers around diagnosis, treatment and access to good-quality information and support, it deeply concerned me."
> *Member of Parliament*

Over ten cross-party parliamentarians have so far sent letters to Ministers. There have also been more than ten parliamentary questions tabled on IPF. We have provided assistance to people with IPF and their families to help them engage with their constituency MPs and local health authorities, such as providing draft template letters to send to their MPs.

Speaking to MPs in parliament about IPF

Service mapping

In the first half of 2014 the IPF project manager conducted telephone interviews ranging from 30 to 45 minutes with over 20 consultants and nurses with an interest in IPF. This informed project activity and also led to a summary of ILD services around the UK being produced that is aimed at people with IPF and their families. This is now available on the online IPF hub. In the month after this was soft launched there were 271 visits to this page. We also mapped the locations of pulmonary fibrosis support groups around the UK. This page has had almost 1,500 visits since being launched in August 2014.

Personal organiser

People with IPF often experience fragmentation between different local and specialist services. To help them better manage their condition we developed an IPF personal organiser. This is a structured booklet that has guidance and space to write notes to help people with IPF feel more in control of their condition. The content and design were reviewed by a focus group of people with IPF and carers. A number of consultants and nurses were also asked to review the materials. The organiser will be piloted and evaluated in two hospital centres in the UK over the first six months of 2015.

> "I think this [personal organiser] is absolutely brilliant. I can keep everything in one place so when I see my doctor I can remember what I've been told by other health care professionals"
> *Person with IPF*

Supporting health care professionals

"The day has inspired me to fight even harder for my patients' rights" *Health care professional*

During autumn 2014 we held four study days for health care professionals with a special interest in respiratory. As a result of feedback from our BLF Professionals all the events had at least one presentation on ILDs and another on end of life care. This meant we reached an audience of general respiratory nurses who may not have had an initial interest in ILD or IPF. Across the events, the sessions on difficult, end-of-life conversations and IPF/ILD look to have had the greatest impact when judged according to planned changes in practice reported by delegates and also their feedback on the most enjoyable or beneficial aspects of the event. During our event in Exeter, the first half of the day focused on ILDs and the second half focused on palliative care.

As well as holding health care professional events, we piloted ILD shadowing days with two nurses from Northern Ireland spending a working day with an experienced ILD nurse. Their feedback was that shadowing is extremely valuable. As a result we are now extending this opportunity in our BLF Professionals scheme.

Information stand at a health care professional event

Looking forward

We will build on a successful first year of the IPF project by continuing to call for action on the key points in our IPF Patient Charter. Ensuring we continue to have strong relationships with people with IPF and their families, health care professionals, politicians and policy makers across the whole of the UK will be central to this.

In the next year from November 2014 to November 2015 our plans include:

- Carrying out a large scale patient experience survey
- Piloting our IPF personal organiser
- Evaluating the IPF information pack
- Helping set up and support more pulmonary fibrosis support groups
- Holding further IPF Meet the Expert events around the country
- Developing a virtual campaign group inviting representatives with IPF and carers from across the UK
- Continuing to develop our online resources for people with IPF and their families
- Providing support and information for health care professionals
- Using World IPF Week to raise even more awareness
- Continuing to promote IPF awareness through the media
- Launching the first ever IPF campaign report in parliament and continuing to influence key policy makers within the Department of Health, NHS and commissioning across the UK

These plans are all dependent on the resources available. If you are interested in supporting the project then we'd love to hear from you.

We will strive to improve our support for everyone affected by IPF and raise funds to support this important work. We could not do all that we do without continuing input from all our supporters, thank you.

Supporting us

Corporate partnerships

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

Email: corporate@blf.org.uk

Patients or carers

If you have IPF 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 IPF research and support.

Email: patientvoice@blf.org.uk

Health care professionals

If you are a health care professional and would like more information on the IPF project, please contact our stakeholder engagement team.

Email: HCP@blf.org.uk

Resources

The BLF has lots of information about IPF and living with a lung condition.

You might find these useful:

- Idiopathic pulmonary fibrosis leaflet
- Idiopathic pulmonary fibrosis and other types of interstitial lung disease booklet
- Looking after someone with a lung condition booklet
- Coping with the final stages of chronic lung disease booklet

If you would like any of these health information resources you can order online or telephone.

- To order online go to www.blf.org.uk/publications
- To order by telephone call our helpline on 03000 030 555

We also have lots of information about IPF available on our website at www.blf.org.uk/IPF

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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Our IPF Patient Charter

Idiopathic pulmonary fibrosis (IPF) is a chronic, progressive and incurable lung disease.

Killing over 5,000 people a year in the UK – it is on a par with far better-known conditions such as leukaemia. The condition has been on the rise for decades, but remains poorly understood and with limited treatments and no cure.

The disease often acts with devastating speed, with barely half of patients surviving the three years after diagnosis.

With rates of IPF continuing to rise, the British Lung Foundation (BLF) is calling for more to be done to help fight IPF and the devastating impact it has on the lives of patients and their families.

The BLF believes that people with IPF and their families have the right to:

1. Timely and accurate diagnosis and care, involving an appropriately skilled, specialist multidisciplinary team
2. Access to seamless, well-integrated health and social care services, including ambulatory and domiciliary oxygen services personalised to the needs of IPF patients
3. High quality information about the condition, including full details of all treatment, clinical trials, transplant, support and service provision options available to them
4. Specialist palliative care and end-of-life care; supported by the Gold Standards Framework where appropriate
5. Access to dedicated peer support networks, both for patients and their carers, in person or digitally

The BLF calls upon UK governments and NHS leadership to:

6. Ensure sufficient funding is made available for the FULL implementation of the NICE guidelines for IPF
7. Build and resource clinical networks to ensure seamless care between providers at all stages of the patient pathway, and a co-ordinated approach to IPF management including access to clinical trials
8. Increase funding for IPF research to a level that will tackle the considerable, and growing, impact of the disease in the UK
9. Recognise the urgency of need in patients with rapid disease progression, via swift access to specialist care, appropriate prioritisation on transplant waiting lists, and prompt social care assessment and response
10. Conduct awareness campaigns to improve public and primary care recognition of the condition and its symptoms, and encourage employers and providers of insurance, travel and financial services to better meet the needs of people with IPF

Our ILD research

The BLF continue to fund research into ILD including IPF, with over £1.7 million awarded so far. We aim to drive research in areas where we feel we can make a real difference to patient outcomes.

In the last year we have developed a new research strategy to direct our spending more clearly than ever before. We identified a set of priorities through collaborative working with patients, researchers and carers, to ensure that we fund research projects that will not only be scientifically robust but that will make the maximum difference to people living with a lung disease.

As part of this, in February 2014 we organised a meeting with over 20 patients, carers, researchers and clinicians to discuss broad research priorities for ILD. This helped inform our organisational research strategy.

Looking forward to 2015 we are setting-up an ILD research advisory board with researchers, clinicians, patients and carers to determine specific priority research areas that need to be tackled in order to improve care for people who have IPF or another ILD.

In 2014 we awarded an additional £170,000 towards ILD research. The two new studies we funded are summarised in the table below.

ILD studies funded in 2014

Can we reduce lung scarring in pulmonary fibrosis? (lab. study) *Lead researcher:* Prof. Simon Johnson University of Nottingham *Amount:* £49,781 *Duration:* 12 months, starting Mar 2015	This pilot study will examine the extra-cellular matrix (ECM) protein in the lungs. In fibrosis, cells known as fibroblasts produce too much ECM protein making the lungs smaller, stiffer and reducing oxygen uptake leading to breathlessness, cough and respiratory failure. The ECM in IPF may be physically different which prevents its removal by normal mechanisms. This difference may be the action of proteins which link ECM proteins together stabilising the structure. The study will investigate if blocking the proteins that cross-link the ECM reduces fibroblast growth, fibrotic signals and allows ECM to be broken down normally both in isolated cell preparations and in a mouse model of fibrosis.
Better prediction and treatment of IPF (lab. study) *Lead researcher:* Prof. Donna Davies University of Southampton *Amount:* £119,975 *Duration:* 24 months, starting Apr 2015	One obstacle both to development of new treatments to IPF is that the disease course can vary considerably in different patients. Doctors currently have no way of predicting the disease course. This study will evaluate lung cells and lung washings from affected and unaffected regions of patients' lungs to identify biomarkers that might give insight into disease mechanisms and also try to identify patients who may have disease that is present in what are currently considered 'normal' regions of their lungs. This information will help with clinical trial design in the long term provide effective targeted therapies and biomarkers for IPF patients.