



**British
Lung
Foundation**



British Lung Foundation
Leading the fight against lung disease

Annual Review **2012/13**

Contents

Welcome	3
Funding life-saving research	6
Preventing lung disease	10
Offering hope and support	18
Making it happen	28

Welcome

It has been an exciting and also challenging year at the British Lung Foundation. As chair and chief executive, our feelings of pride and excitement about the organisation are as strong as ever, as there is so much to do and achieve.

Lung disease affects millions of people in the UK and we have spent time over the past year planning how we can reach and support more of those people to greater effect, while continuing our important work funding vital research and ensuring our future sustainability in what continues to be a challenging financial climate.

Our long-term aim is to fund more research into understanding, alleviating, treating, curing and preventing lung disease. Our ground-breaking, world-class research programme is contributing to big improvements to lung health, but we can do much more, and this will be a key focus for the BLF going forward.

We also remain committed to supporting anybody affected by a lung condition through our helpline, Breathe Easy groups, health information, our vibrant web community and the BLF Nurses Programme.

We will continue to campaign tirelessly on the issues that matter to people with lung disease, including better access to and higher quality of care for patients, more effective tobacco controls, and increased awareness of the dangers of asbestos.

In the next few years our work will focus particularly on chronic obstructive pulmonary disease (COPD), mesothelioma, idiopathic pulmonary fibrosis (IPF), lung cancer and children's lung diseases, but we remain committed to supporting everyone with lung disease, across a whole range of different conditions.

Focusing our strategic direction to help us reach more people and ensure our future sustainability has involved a number of changes at the organisation in the past few months. We have said goodbye to some of our staff members, and we would like to thank all the people who have left us in the past year who have worked so hard on behalf of everyone that we serve. We wish you all the best for the future.

We've welcomed new colleagues too. Amongst them is Professor Sir Michael Marmot, one of the world's leading authorities on health inequalities, who became president of the BLF in April 2013. With more than 35 years' experience in health-related research, Professor Marmot's expertise in the impact of social factors on health will be an invaluable resource for the BLF. We also welcomed Professor Stephen Holgate as the new chair of our scientific committee in July, and Dr Noel Snell as our director of research in October.

As well as putting plans in place to ensure a sustainable future for the BLF, we achieved a great deal during 2012/13. As you read about our successes, we hope you'll be as excited about the year ahead as we are.



Peter Dolphin
Chair



Dr Penny Woods
Chief Executive

What do we do? And how do we do it?

1 We fund vital research into understanding, treating and preventing lung disease.

We invested £1.1 million in projects to fight lung disease in 2012/13.



£1.1million

2 We want to prevent lung disease in the first place, by campaigning for positive change in the UK's lung health and promoting greater awareness.

13,000



This year, we assessed the lung health of 13,000 people in Wales using our breath questionnaire.

3 We offer hope and support at every step so that no one has to face lung disease alone.



9,000

We supported 9,000 people through our helpline during 2012/13.

32



We helped 32 young researchers attend major respiratory conferences – that's five more than last year.

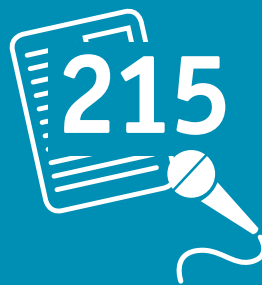


We invested £250,000 into finding out the state of lung health in the UK.

£250,000



We educated 25 MPs about OSA and showed them how they can help improve treatment and care at our parliamentary reception in April 2013.



We generated 215 articles, news reports and interviews to increase awareness of the dangers of smoking, with the potential to reach 210 million people.

7,000

Our BLF nurses gave expert care to more than 7,000 people with lung disease in their homes and communities.



More than 300 fitness instructors have now received BLF-endorsed training to provide exercise for people with lung conditions.

We invested £1.1 million into **world-class research** to save, prolong and improve lives.

Supporting people with lung conditions is vital.

Changing people's behaviour to stop them getting lung problems in the first place is absolutely crucial.

But only research has the power to eradicate the often devastating lung conditions that affect millions of people across the UK.

That's why we've invested £1.1 million this year into innovative projects to fight diseases ranging from lung cancer to tuberculosis.

Saving lives with our research projects

This year:

- **We invested £250,000 into major new research on the state of lung health in the UK. We'll use the results to campaign for better service provision across the UK, and plan the most effective research for the future, to save the most lives.** The Respiratory Health of the Nation project, run by Professor David Strachan and colleagues at four UK universities, aims to develop a better understanding of lung health in the UK and how this compares to other western nations. The project will help to inform our work and enable us to identify areas of greatest need. **Find out more on page 8.**
- We co-funded a £25,000 lung cancer research grant with Cancer Research UK. Dr Corinne Faivre-Finn at the University of Manchester will run a 30-month trial to determine if it is possible to give higher doses of radiotherapy to lung cancer patients safely. If successful, the project has **the potential to improve survival rates for lung cancer** in the UK.
- Our Burrow Hill Training Fund gives money for **lung research related to the armed forces**. This year, we gave grants totalling £32,000. We also gave a total of £730,000 towards research projects focused on **asbestos-related disease**.

Helping researchers to share knowledge and improve their skills

This year:

- We gave travel fellowships to 32 lung researchers starting out in their careers so they could afford to go to the European Respiratory Society and American Thoracic Society annual conferences, in Vienna and Philadelphia. They learned about the latest in lung research from top experts, and presented their own studies. **Our support for today's young researchers helps them become tomorrow's leaders in the fight against lung disease.**
- **We supported researchers to improve their skills and knowledge in other ways too.** At the British Thoracic Society Winter Meeting, we held a session where BLF grant-holders showcased asbestos-related disease research. We took part in another session to let researchers know about our funding opportunities and gave out our 'Early Career Investigator Awards', which recognise younger respiratory researchers' excellence.
- **The prestige of our research work has been recognised**, with the results from BLF-funded studies appearing in world-class scientific journals including *Thorax*, *Proceedings of the National Academy of Sciences of the United States of America*, *the European Journal of Immunology* and *the European Respiratory Journal*.



We invested £250,000 into finding out the state of lung health in the UK.



“ If everyone has their lung function measured, we can better identify people who might have early lung disease. ”

Professor Strachan, from St George’s, University of London, is leading a £250,000 BLF-funded study into the respiratory health of the nation.

“ I was asked by the BLF scientific committee to lead a new research study that aims to provide a detailed picture of lung disease in the UK.

The Respiratory Health of the Nation project will help the BLF to create informed campaigns to raise awareness of respiratory disease, and persuade external organisations to fund more research into lung conditions.

The statistics we have around lung disease become out of date very quickly, and we need to get back up to speed. This project, which started in January 2013 and runs for three years, will give us new information in a lot of different areas.

Four studies are taking place at St George’s, University of London, University of Nottingham, University of Edinburgh and Imperial College London. We will then bring all these projects together to provide an overall assessment of respiratory health in the UK, as well as comparisons between the UK and other countries.

For people with lung disease, we’re trying to find out more about the journey that takes you from your community

into primary care, then to secondary care, and then through a range of health outcomes. Because we’ll be doing work on geographical variations, looking at hospital admission rates and how people with lung disease use different services, we will be in a position to see if there is a lot of variation between different areas that perhaps needs to be investigated.

As well as looking at lung disease, we’re very interested in lung health. One source of information that we will examine is the UK Biobank project – the biggest and most detailed database of biomedical information in the world. It holds information on 500,000 people from across the UK, including lung function.

The UK Biobank population will be useful to monitor people who have never smoked and who have good lung function. One thing we would like to be able to do is to make some recommendations about whether lung function tests should be used more routinely as part of normal health checks. If everyone has their lung function measured, we can better identify people who might have early lung disease.

Our ground-breaking new research facility

Mesothelioma is one of the most difficult cancers anyone can face. Found in the lining of the lungs, it's almost always fatal. And it's on the increase, now killing more people each year than cervical or testicular cancer. Our pioneering new facility, Mesobank, was founded in September 2012 to help fight this deadly disease.

Most people with mesothelioma were exposed to asbestos in the 1950s, 60s and 70s. Years later, they're paying the price. The average life expectancy for someone diagnosed with mesothelioma is just eight to 14 months.

This devastating cancer kills 2,400 people each year in the UK – a figure that is still rising. Mesothelioma deaths in the UK have nearly quadrupled in the last 30 years, and are likely to peak later this decade.

Effective treatment for mesothelioma is extremely limited – but our new research facility is working very hard to change this.

Our new 'Mesobank' collects and stores tissue from people who have the disease, which researchers can use when looking for new treatments. It is the first dedicated bank of mesothelioma tissue in Europe.

We launched the Mesobank with the Mick Knighton Mesothelioma Research Fund, which was established 10 years ago by Chris Knighton in memory of her husband Mick, who died of mesothelioma.

We are now working even more closely with the organisation so that we can strive to fight mesothelioma more effectively



◀ Chris Knighton receives an MBE at Buckingham Palace for her work raising money for mesothelioma research.

together. Chris was awarded an MBE in 2012 for her work with the Mick Knighton Mesothelioma Research Fund. **Find out more about her fantastic fundraising efforts on page 30.**

And find out how we're campaigning for more mesothelioma research funding on page 13.

We work hard to **prevent**
people getting lung disease
in the first place.

Lung disease affects 1 in 5 people in the UK. That's more than 12 million individuals. Sadly, 110,000 of them die each year.

We're dedicated to making a reduction in these terrible numbers. We'll make this happen by spreading the word to everyone about the causes and signs of lung disease and how to prevent it, as well as influencing decision-makers to use their power to fight lung disease.

We've achieved a huge amount this year.

Leading the fight against smoking

Despite significant efforts to stop people smoking, a quarter of adults in the UK still light up. Cancer, chronic obstructive pulmonary disease (COPD), heart disease and stroke are just some of the very real risks of smoking – and of inhaling second-hand smoke.

We're fighting to protect children from the dangers of second-hand smoke in cars and to stop tobacco companies using clever marketing tricks to attract young people. This year, we generated 215 media articles, news reports, and interviews relating to our campaigns on the dangers of smoking, with the potential to reach more than 210 million people.

This year:

- **We continued the battle to safeguard children from second-hand smoke.**

165,000 episodes of illness, 9,500 hospital admissions and 40 infant deaths: that's the massive – and unacceptable – impact of second-hand smoke on children in the UK each year. Children travelling in cars where someone's smoking are particularly at risk: even with the window open or air conditioning on, smoking can produce concentrations of pollution that exceed World Health Organisation safe limits. Since 2010, we've been campaigning hard to make smoking with children in the car illegal. We made good progress in 2012-13.

- **At Westminster:** We had hoped that the Smoke-free Private Vehicles Bill,

banning smoking in cars with children, would continue its progress after Alex Cunningham MP took it to the House of Commons. We were disappointed when it officially lapsed at the end of the parliamentary session, defeated by scheduling rather than a debate and vote. However, our fight for a ban on smoking in cars with children continues. In February 2013, the then **Public Health Minister, Anna Soubry MP, expressed her personal support for a ban.**

The Department for Health also ran a 'Smoke-free homes and cars' media campaign. Since then we've seen some promising progress, including indications that the government considered introducing a ban in the Queen's Speech in May 2013. While they didn't this year, we continue to work hard to influence key decision-makers, moving **ever closer to achieving our aim.**

- **At Holyrood:** In spring 2013, the Scottish government published its Tobacco Control Strategy, which promised to prioritise raising awareness of the damage caused by second-hand smoke. This comes on the back of other positive moves against smoking in Scotland, including banning cigarette vending machines and displays of tobacco products at shop tills – all of which the BLF campaigned for.

- **At Stormont:** The Northern Ireland Assembly published its Tobacco Control Strategy in early 2012, outlining its commitment to dealing with second-

hand smoke. We're now pushing the assembly to set a date for a public consultation on banning smoking in cars with children. We're part of the steering group for this consultation.

- **At the Senedd:** In large part thanks to campaigning by the BLF, the Welsh Assembly has already committed to considering legislation to protect children from smoke in cars, if a three-year behaviour change campaign they're rolling out doesn't succeed.
- **We've also campaigned to protect young people from tobacco marketing.** Most forms of tobacco advertising have been banned in the UK for years. But one remains: companies are still allowed to advertise on their packaging. Many use clever marketing techniques to attract young smokers or perpetuate old myths about 'healthier' brands of cigarettes. We want all cigarettes in the UK to be sold in standardised packaging. The Scottish government pledged to make this happen as part of its Tobacco Control Strategy. We were dismayed when the UK government delayed doing the same thing in July 2013. We continue to **push Westminster to make standardised packaging law**, encouraging people to write to their MP and ensuring greater awareness of this issue via the media.

“ A child’s exposure to second-hand smoke in the confines of a car is a major public health issue that needs action as well as words. I am pleased to see support for this measure within government. They must now take the initiative and legislate.

Alex Cunningham,
MP for Stockton North



Children visit the doctor more than 300,000 times every year in the UK because of passive smoking. Support the BLF campaign to ban smoking in cars with children by writing to your elected representative. Find out more at www.blf.org.uk/Smoking-in-cars

Protecting people from deadly mesothelioma

Did you know that, every week, an average of 20 tradespeople die in the UK from exposure to asbestos? That makes it the biggest single cause of work-related deaths in this country.

When disturbed and inhaled, asbestos fibres can cause the terminal cancer mesothelioma. Using asbestos may now be illegal, but it's still present in more than 14 million homes, according to estimates.

Last year, our **Take 5 and Stay Alive** campaign was launched to save lives by encouraging people undertaking DIY to take five minutes to learn how to spot asbestos and what to do if they find it. This year, we'll re-launch the campaign to specifically target builders, plumbers, electricians, joiners, and other tradespeople to help protect them from the risk they may be facing at work.

Find out more at
www.take5andstayalive.com

Campaigning for more mesothelioma research funding

Our new research facility (find out more on page 9) isn't the only way we're fighting mesothelioma. **We're also demanding that more funding is dedicated to researching the cancer and finding new treatments and cures.**

The new Mesothelioma Bill is passing through the House of Lords and is expected to become law in late 2013 or in 2014. The bill mainly concerns compensation for people who have contracted mesothelioma. However, we've pushed for money dedicated to research to be legislated in the bill too. We raised this issue in the House of Lords during the second reading, and continue to work with several peers to push the issue further up the political agenda. **Find out more about this campaign on page 14.**

9
5
0
0

Second-hand smoke is responsible for 9,500 hospital admissions for children each year, according to the Royal College of Physicians.



“The BLF has done **fantastic work to fund research into mesothelioma.**”

Lord Alton of Liverpool is a life peer in the House of Lords.

“Mesothelioma is a type of cancer that affects the thin lining in your chest and abdomen. Each year, 2,400 people in the UK die of this deadly disease. Death rates are yet to peak, and more research is needed in order to find treatments and a cure.

I had long been aware of the need for greater research funding into this condition. Compared to other cancers, mesothelioma has been and remains chronically underfunded in terms of research into potential new treatments and cures.

I am keen to work through parliamentary channels, and in particular to try to amend the Mesothelioma Bill to ensure a statutory footing for future mesothelioma research investment. I decided to work with the BLF on their campaign because their aim is very much in accordance with my own.

The BLF has done fantastic work to fund research into mesothelioma, and I know they work very hard to ensure that this work benefits mesothelioma

patients with a view to hopefully, one day, finding a cure for this terrible disease.

The organisation has championed this cause and has been extremely supportive of my efforts to raise the issue up the political agenda. They have also been crucial in helping me to try to amend the Mesothelioma Bill by providing briefing materials, expert advice and case studies.

I greatly admire their work in this area, as well as their general commitment to supporting all patients with lung disease.

Working with the BLF on this issue has meant that many, many more parliamentarians and, crucially, the government, are now aware of the desperate need to ensure greater funding into mesothelioma research in future.

I hope that the government will be obliged to take action on this important issue as the bill moves through parliament.

I look forward to continuing to push for greater funds for mesothelioma research in the future.



Putting obstructive sleep apnoea firmly on the agenda

Obstructive sleep apnoea (OSA) is a common disorder that stops you breathing as you sleep. Without treatment, it is linked with serious consequences, including heart disease, stroke and diabetes. Despite this, up to 80 per cent of people with the condition go undiagnosed.

We're campaigning to raise awareness of OSA, so more people are diagnosed and get the treatment they need. Our campaign has been praised by many experts, including those at the British Thoracic Society and British Sleep Society.

This year:

- **More than 35,000 people have now used the BLF's online Epworth Sleepiness Scale** to see if they have signs of OSA and should go to their GP. That's up from 24,500 last year.
- We launched our **OSA Next Steps policy report**, detailing how we want the government to help raise awareness of OSA and the improvements needed in treatment and care. The launch at the House of Commons was attended by 30 parliamentarians, who we convinced to support our campaign.
- We started what we hope will be the **largest-ever survey of people with OSA in the UK**, to give us the facts to help us plan the most effective campaign and convince decision-makers that

it's vital to tackle OSA. In 2013, we also finished a project to **map sleep clinics in the UK and areas of the country with high potential OSA risk**.

- We ran four community events in County Durham offering information and free screening for OSA. We put OSA on GPs' radars too, sending out information packs to all local surgeries and offering OSA training to GPs. Our GP guide is available to GPs across the UK via the BLF website.
- We developed and started to deliver a programme of training and events that we can take into workplaces to raise awareness of OSA.

Improving asthma care

Asthma is the most common lung disease in the UK: 5 million people have it. That's why we've prioritised improving diagnosis and care with our new asthma project. Working with other stakeholders, we will support health care professionals to improve their skills.

This year:

- We secured funding from the Department of Health, the Scottish government and a consortium of pharmaceutical companies for **pilots in Grampian, Scotland and Stoke and North Staffordshire, involving 100 GP practices**. We expect the pilots to improve diagnosis and care for thousands of people with asthma.

Zzz
35,000+

More than 35,000 people have now used the BLF's online Epworth Sleepiness Scale to check if they have signs of OSA.

Raising awareness of lung disease up and down the UK

National campaigns to improve the lives of people with lung conditions are crucial. But so is getting out on the road and spreading the word about lung disease in local communities. Our offices in the devolved nations and our local Breathe Easy groups are making change happen, little by little.

This year:

- We held **'Love your Lungs' events nationwide to spread the word about chronic obstructive pulmonary disease (COPD)**, a debilitating condition where long-term damage to the lungs causes breathing difficulties. Often working with the NHS, we tested 1,647 people for COPD at public events, advising 21 per cent of them to visit their GP because they showed signs of lung disease. People who responded to our surveys said the events helped them to take
- We also **trained health care professionals about COPD**, to improve how they treat people with the condition. East and North Hertfordshire Clinical Commissioning Group commissioned us to run workshops for 60 GP practices in the area. We also educated volunteers in Haringey, London, about lung cancer. Everyone who responded to our surveys about the training sessions rated them as 'good' or 'excellent'.
- We put information about lung disease and the BLF in 82 per cent of community pharmacies across Wales, working with Public Health Wales and Community Pharmacy Wales. More than 13,000 people took our breath test questionnaire. We launched this campaign at Boots in Cardiff, with entertainment from award-winning male choir Only Men Aloud. Lesley Griffiths,

“ The support we received from the BLF in the design and rollout of awareness-raising and screening campaigns across our local area has been superb. They helped us to access many local people who we would not normally be able to reach.

Gail Lett, Senior Commissioning Manager for Long Term Conditions,
NHS Heywood, Middleton and Rochdale

”



◀ Testing local people for COPD at the BLF's Love Your Lungs campaign in Rochdale.

the then Minister for Health and Social Services and Professor Mark Drakeford, then Chair of the Welsh Assembly's Health and Social Care Committee, came along to offer their support.

- In Wales, we were disappointed not to see much about lung health in the Together for Health programme, the nation's five-year vision for the NHS. So we campaigned to **persuade the assembly to give lung disease higher priority**. It worked: the Respiratory Delivery Plan for Wales will now form part of Together for Health.
- Breathe Easy groups in the north of the country **campaign for politicians to prioritise local respiratory health on the political agenda**, with 12 groups writing to their MP. Breathe Easy Rotherham put their points across

to Anna Soubry, the then Minister for Public Health, when she visited them in March 2013. Groups and health care professionals in the area also held 30 awareness-raising events for World COPD Day. People with lung disease and their carers can now pick up information about their condition from 106 leaflet display boards in local hospitals and GP surgeries.

- Breathe Easy Causeway, in Northern Ireland, marked No Smoking Day by **visiting a local primary school to teach children about the dangers of smoking**. They also launched a competition for children to design a poster which showed each part of the lungs and discouraged smoking.

13,000



This year, we assessed the lung health of 13,000 people in Wales using our breath questionnaire.

We're here to offer **caring support** and **vital information** for people affected by lung disease.

A surge of emotions. Lots of questions. Wondering what the future holds.

That sums up most people's reaction to finding out they have a lung condition. It can be a frightening, frustrating and overwhelming time.

We're there from the word go with vital information and support for them, their families, friends and carers. And we stay with them throughout, always available with the help they need, so no one has to face lung disease alone.

We supported hundreds of thousands of people in 2012/13.

Friendly experts just a phone call away

Questions. People with lung disease usually have lots of them – when they've just found out about their condition and beyond. Their family and friends often need advice too.

The respiratory nurses, welfare benefits advisers and counsellors on our national helpline are there to help with everything from medical questions to emotional support and queries about financial help.

A friendly voice at the end of the phone, with the right information and a few reassuring words, can make all the difference to a person anxious about their condition, or about someone they love.

“ The nurse adviser was so easy to talk to. She quickly established a rapport and imparted information in a friendly, professional manner. I can't thank her enough for our conversation. It was life-affirming and life-changing. She was also efficient as the written information underpinning our conversation was dispatched the same day.

Pat Parry, helpline caller

“ The BLF Helpline nurse answered two years of questions in half an hour. I could finally concentrate on getting well again.

Rachel Macgregor, helpline caller

This year:

- Our helpline **received a massive 12,200 calls and 3,240 emails**, giving people the information and reassurance they needed, so they went away feeling happier and more in control. In total, we offered support and advice to almost **9,000 people** via the helpline in 2012/13.
- Our **helpline staff gave callers excellent service**. They answered 98 per cent of calls within six rings. People were so impressed that more than half (53 per cent) came back to the helpline for more support. And, as always, calling our helpline never costs more than a local call.

Call our
helpline
**03000
030 555**



9,000

We supported 9,000 people through our helpline in 2012/13.

Giving out first-class information

Often, people with lung disease just want the facts. How can I expect to feel with my condition? How will it change my life? What treatment is available?

Our huge selection of leaflets, booklets and online information answers all these questions and more, about many different types of lung disease. They help people with lung conditions, and their family and friends, learn about their disease and plan for the future.

All our information is accredited by NHS England through its Information Standard scheme, so you know it's reliable, accurate and trustworthy.

This year:

- **We sent out more than 900,000 booklets, leaflets and factsheets** to people on all sorts of lung health topics, helping them learn more about the condition that affects them.
- We know that lung disease doesn't just affect the person with the condition. It can change their family and friends' lives too, as they often provide some of their care. An area we really focused on in 2012-13 was **providing information for family, friends and carers**. We had more than 20,000 visits to the 'carers' section of our website this year, and we also sent out more than 13,000 copies of our booklet, *Looking after someone with a lung condition*.

“ **What an excellent booklet you have produced! I think it would be useful to any carer, not just one caring for someone with a lung condition.** ”

Jo Ivory, carer

- As part of our campaign to tackle obstructive sleep apnoea (OSA), **we produced a pack to help health care professionals and people with OSA learn about the best ways to manage the condition**, from symptoms and diagnosis to how to live with OSA day-to-day.
- We continued to produce **top-class information on how to manage chronic obstructive pulmonary disease (COPD)** for health care professionals to give out to patients. In 2012-13 we sold more than 17,000 COPD self-management packs, 3,700 exercise handbooks, and just over 5,000 *Living with COPD* DVDs, helping patients to take control of their condition.
- Finding out you have COPD can be overwhelming and it's often difficult to take in all the options you might have for treatment. With this in mind, the BLF, along with the Respiratory Clinical Network in the North West, produced a **7 steps to best COPD care leaflet**, letting



900,000

We sent 900,000 booklets, leaflets and factsheets to people affected by lung disease this year.

people know about the different ways they can be treated and helping them to manage their condition better.

- Who better to tell the BLF what information we should produce than people affected by lung disease themselves? This year, **we worked closely with patients and health care professionals** to make our information on healthy eating, exercise and how to get the best out of an appointment with your doctor as relevant and useful as possible.
- **The British Medical Association (BMA) recognised that our information is high quality, accessible and well written.** Our information for families, friends and carers was highly

commended by the BMA, ahead of its annual patient information awards. Our online information about OSA in children, including a powerful video of a child stopping breathing in his sleep, was also commended.

- We're always looking for new ways to make our information more accessible and easier to digest for everyone. **Our regular online surgeries – online presentations from experts posted on our website – let people access key information about their lung condition easily.** This year, our experts hosted online surgeries on mesothelioma, IPF and stopping smoking, among many other topics.

The British Lung Foundation provides clear and trustworthy information about many types of lung disease, as well as advice on managing and living with a lung condition. To find out more or order a publication call the BLF Helpline on **03000 030 555** or go to **www.blf.org.uk/publications**



BLF nurses: providing excellent care on the frontline

BLF nurses make a huge difference to people who are ill with lung disease. Up and down the country, they care for people in their own home and in their communities so patients can leave hospital earlier – or stay at home for their entire treatment.

They also go to awareness-raising events nationwide, helping us spread the word about lung disease so people can recognise the signs and get treatment for symptoms early on.

All BLF nurses work as respiratory specialists in hospitals and clinics across the UK, and receive extra training and support from the BLF.

“ We were all very impressed with the choice of speakers and topics chosen for the training day. The whole team thought it was well worth travelling up, and we all came away with ideas for our own practice. ”

Steve Parse, head of BLF nurses team in Plymouth

7,000

Our BLF nurses gave expert care to more than 7,000 people with lung disease in their homes and communities.

This year:

- **Seventeen new BLF nurses joined the team.** We now have 110 nurses giving expert care to more than 7,000 people with lung disease in their homes and communities. We also recruited our first nine nurses in Northern Ireland, which means we now have BLF nurses in all four UK nations. We trained seven of our new nurses thanks to funding from charitable trusts.
- BLF nurses potentially saved lives at **more than 100 awareness-raising events across the UK**, letting people know about the signs of lung disease and what to do if they have symptoms.
- **We improved the way we train our nurses**, inviting local respiratory professionals to come along to training days for the first time to share their knowledge and build links with the BLF nurses.

“Patients feel reassured that the person looking after them knows what they’re doing and can manage their condition effectively.”



Temitayo Magbagbeola is a BLF nurse in south London.

“I became a BLF nurse in 2009 after working as a clinical ward sister on a medical ward. I have always worked on a respiratory ward and have become really passionate about respiratory nursing. I have completed some important training courses through the BLF – you get to know the latest developments in respiratory care and update your skills.

Specialist nurses have a very important role as patients feel reassured that the person looking after them knows what they’re doing and can manage their condition effectively. It makes them feel that they have got a good level of support.

My day can be very varied. Usually I review around three to five patients each day in the nurse-led clinic or at patients’ homes. We see all sorts of different respiratory conditions but mainly COPD or asthma patients.

People like the fact that I’m associated with the BLF. The organisation is well

known for its research and people know that the care they are given is evidence-based and that the nurses have been well trained. The fact that the nurses are backed by the BLF is seen as a real plus.

The wife of one of my patients said she would always remember the BLF nurse who came to see them and she sent a letter of appreciation to the BLF when her husband sadly passed away. It really does mean a lot to people.

Lately I have been working with a local Breathe Easy group and I’m really looking forward to becoming more involved and seeing how we can assist them. It’s a great place for people to get help when they feel down. It gives them a voice and somewhere to go, and they can also get advice and information from health care professionals. I plan to organise some speakers for them and visit when I can.

I feel very proud to be associated with the BLF and to have their support.”

Glasgow's Celtic Park offers an inspiring venue for the RESULTS exercise programme.



Watch a video of the RESULTS sessions at Celtic Park at www.blf.org.uk/2013

Getting people with lung disease active

Exercise is really important for many people with lung disease. Just a little bit of movement can help them improve and manage their condition.

But it isn't always easy to keep up with a regular exercise class or fitness regime. That's why we give people with lung disease lots of opportunities and specialist support to help them keep fit.

set up classes, and helping people with lung conditions find specialist fitness instructors in their area.

- In Glasgow, we took an innovative approach to getting people with COPD exercising and improving their health. Working with Celtic Football Club and the NHS, our RESULTS programme held **exercise and education sessions for people with early-stage COPD at Celtic Park football stadium**. Holding the sessions in an iconic sports venue helped grab people's attention and get more people coming along.
- Our Breathe Easy group on the **Isle of Wight won £9,000** from their local Clinical Commissioning Group to develop BLF Active in rural areas of the island.

This year:

- There are now **more than 300 specialist fitness instructors nationwide** who have received BLF-endorsed training to provide exercise classes for people with respiratory problems.
- **Forty-seven instructors completed this training** in 2012-13. We support our instructors through the BLF Active scheme, providing tools to help them

Find out more about Breathe Easy Isle of Wight and their fantastic fundraising successes on page 27.



More than 300 fitness instructors have now received BLF-endorsed training to provide exercise for people with lung conditions.

Influencing the right people to save and improve lives

The practical support and information we provide for people living with a lung condition improves hundreds of thousands of lives each year.

But there's another crucial way we can help to make things better. We campaign nationally and locally to improve treatment and care for people with lung disease.

This year:

- We focused our efforts on **improving treatment for idiopathic pulmonary fibrosis (IPF)**, a chronic, progressive and incurable lung disease that kills more than 4,000 people a year in the UK – around the same number as better-known conditions like leukaemia. That number looks set to rise.
- During 2012/13 we held two patient events in Leeds and Warrington to give advice and information to people living with IPF. We found there was a thirst for information from patients and their families, many of whom had travelled miles to attend. Ninety-seven per cent of people who came to the Leeds event said it was either 'excellent' or 'good'.
- We followed these events with a **roundtable seminar for 30 clinical leaders, patients and carers**, where we discussed what they thought about IPF treatment and care. We're now putting together an 'IPF Patient Charter', outlining a range of improvements that need to be made in treatment and care for people with IPF. Our work on IPF will continue in 2013-14, when we'll be producing more information for people affected by the condition, supporting patient groups and campaigning for better services.
- Nothing influences decision-makers more strongly than **hearing about the experiences of people with lung disease themselves**. We give patients training and support them to tell their stories where it matters. For example, in the Midlands, thanks to funding from the Big Lottery Fund and West Midlands Strategic Health Authority Respiratory Board, we trained 16 'user representatives' on how to use their experience to influence the review and planning of services in their areas. In London and the South East we trained 27 people, and published a handbook for user representatives. We also published a handbook for health care professionals about the best way to work with patients.

Connecting people, sharing experiences, improving lives

Feeling isolated and alone is often a problem for people with lung disease and their families and friends.

Whether someone has a lung condition themselves, or cares for someone who does, they might never have met anyone else in their situation.

Just having a chat with someone who understands what they're going through can make all the difference. It can make them feel instantly less anxious, more in control and more positive about the future.

We make this possible through our Breathe Easy support groups all over the country, where people affected by lung disease can meet others with similar experiences in their community.

We also connect people through the BLF web community, where people can chat on our forums, and through our penpals scheme.

This year:

- Every year, our Breathe Easy groups campaign across the UK during Breathe Easy week to raise awareness of a particular lung condition, so people know the symptoms and how to get help. In June 2013 they did something a little different: they held events across the UK to **raise awareness of Breathe Easy groups themselves**, to encourage people affected by lung disease to join and take advantage of the fantastic support they offer.



The number of visits to our web community each month.

- That's not the only way Breathe Easy groups reached out to others this year. For example, Breathe Easy Nottingham West used a grant from Broxtowe Borough Partnership Lifestyle Fund to give local respiratory staff **200 information packs to hand out to people who had just been diagnosed with COPD** or who hadn't been to the group before. The packs included an invitation to come along to try the group's exercise classes for free. Attendance at the group meetings and exercise classes has increased thanks to this clever initiative.
- Fifteen **new Breathe Easy groups** were set up across England in 2012/13 thanks to support from the Big Lottery Fund, the Peacock Charitable Trust and The Dunhill Medical Trust.
- **Membership of our web community has skyrocketed** to 4,000 people. Our members added 520 new posts a month on average, sharing their stories, meeting other members and getting advice and support. The web community pages are visited approximately 20,000 times each month, with the average visitor staying for half an hour.
- This year, our network of more than 1,300 **penpals** supported each other by email, letter or phone.

“ Breathe Easy is such an important social network. ”



Andy Savage is treasurer of Breathe Easy Isle of Wight and a BLF Active instructor.

“ About 12 years ago my dad was diagnosed with IPF. He took on the role of treasurer at his local Breathe Easy group on the Isle of Wight, but sadly died just three years later.

I was working in London at that time and my dad's doctors asked if I could help out by looking after the group's accounts. Then in 2008 I was made redundant and could get more involved.

I was looking for a job on the island and made a complete career change. I got into fitness, and now I'm a qualified BLF Active Level 4 instructor. I completed the BLF-accredited training at Loughborough College and run classes across the island and at the local hospital, working closely with the pulmonary rehabilitation team. Now we run about 12 classes each week.

People with a lung condition can be afraid of doing exercise because of how breathless they get, but when they finish pulmonary rehabilitation and go on to BLF Active classes they really see the benefits. Some of my members don't just want to do one class a week, they come twice!

Breathe Easy Isle of Wight has gone

from strength to strength, and has been nominated for the first Dame Helena Shovelton Award. It's such an important social network. If people are on their own, it's somewhere they can get a cup of tea, meet people, listen to a speaker, and sometimes we go on outings too.

Last year we were nominated by local people to partner up with the Sainsbury's store in Newport, as part of the company's scheme to support local charities.

I had to give a presentation to staff from Sainsbury's and we were chosen from a group of 25 charities in the area.

From June 2012 to June 2013, starting and finishing with Breathe Easy Week, we held awareness stands every couple of months in store and all the Sainsbury's staff got involved in fundraising too.

We did a rowathon and a coastal path walk, as well as collecting donations in store. Over the year we raised £5,000, most of which we donated to the BLF, while some was spent on equipment for the respiratory department at St Mary's Hospital. It was a great way to get our name out there.



Making it all happen – we couldn't do any of this crucial work without **your support** .

From campaigning to raise awareness of lung disease to supporting thousands of people on our helpline and funding vital, life-saving research, we couldn't do anything without the fantastic support of our fundraisers, donors, volunteers and staff.

Your time and money has made each of our achievements possible.

A massive thank you to all of you.

Fantastic fundraisers

Running. Baking. Cycling. Jumble sales. Raffles. Tributes to loved ones. The ways that people and organisations have raised money for the BLF this year are many and varied. We're hugely grateful for every single effort.

This year:

- **9,000 new people donated to the BLF**, joining the fight against lung disease.
- People often choose to donate to us to remember a loved one who has passed away. **115 people set up online tribute funds** in 2012-13, and we **exceeded our expectations** for this type of donation by 20 per cent.
- **143 people ran the London Marathon** for the BLF in 2013 as part of 'Team Breathe', raising more than £200,000. **You can see photos of our fantastic runners on the BLF Facebook page.**

“ It was an absolute pleasure running for the BLF and I felt incredibly proud to be wearing the vest. It was such a great moment and even the fundraising was fun too. Same again next year? ”

Liz Lock, marathon runner

“ I really enjoyed running the London Marathon for the BLF. The whole experience and being a part of Team Breathe was fantastic. The support on the course and the post-race reception were brilliant. ”

Andy Fraser, marathon runner

- The BLF corporate team works hard to get businesses involved in fundraising for us. This year, they encouraged **50 per cent more employees from companies including Plumbase, Barclays, ResMed and Silverdell to take part in challenge events** such as marathons and bike rides. Plumbase, Exclusive Contract Services and Carlisle Support Services also named us as their **Charity of the Year**, fundraising for us throughout 2013. Next year, the team aims to bring in £550,000 from companies to help beat lung disease.


9,000

We received gifts from 9,000 new BLF donors this year.



“ We have now raised more than £1 million and helped to fund four major research studies into mesothelioma. ”

Chris Knighton is the founder of the Mick Knighton Mesothelioma Research Fund.

“ My husband was diagnosed with mesothelioma 12 years ago and at the time we had never heard of the disease. We were told he had six months to live and there would be no cure, absolutely nothing.

We were urged to claim compensation and then found that Mick had been exposed to asbestos while working in the Royal Navy. The Crown had impunity, so we couldn't make a claim. Mick was 59 when he died, just for doing an honest day's work.

I thought 'I must do something'. I got in touch with the BLF as I wanted to set up a fund specifically for mesothelioma. I had become aware of the lack of research and the fact that so little was known about it.

I set up the Mick Knighton Mesothelioma Research Fund and was told that it would take £100,000 to make any sort of real impact, so that became my first target.

At first I held a fundraising event every month. It took three years to raise the first £100,000 and by then I had met so many people who were affected by this disease,

or had lost someone. From there it has just been onwards and upwards.

About five years ago I set up the Snowdrop memorial funds. I thought my need to do something in Mick's memory would be similar to what other people would feel. We have around 60 Snowdrop funds now. That's the sad fact about mesothelioma. The majority of the money comes from people who have lost someone and realised the desperate need for funding and research.

We have now raised more than £1 million and helped to fund four major research studies into the disease. Receiving an MBE in November was something I would never have dreamed of. I was there very much on behalf of the people I meet and work with. The mesothelioma world is a family and I was representing them.

We have always operated under the umbrella of the BLF but we are now working much more closely together. Hopefully this will mean we can really set the fund up for the future.



The heart of the BLF: our volunteers

What would we do without our volunteers? They provide vital support in our offices and at our events. In return, we always try to give them a great experience and skills they can use in the future.

This year:

- An average of 27 volunteers were in the BLF's offices at any one time, contributing **250 hours each week** to combating lung disease.
- **100 volunteers turned out to cheer on our runners at the London Marathon**, including a full squad of cheerleaders who put on an incredible display. We also welcomed 10 volunteer photographers who helped record the day.
- **We made applying for volunteering positions more straightforward.** Now everyone applying to help us in our offices can do so online, using a standardised system. This makes it much easier to see what opportunities are available, and we can monitor the diversity of our volunteers more easily too.

- **We improved our volunteers' experiences with us** by introducing a new system to consistently manage and evaluate volunteering, making sure our volunteers get enough support.
- **We have prepared volunteering opportunities for our corporate partners' employees**, including volunteering with our choirs and our walking projects. These both play a big part in improving the health of people with lung disease.

“ **The most organised office I've worked in. The BLF was welcoming and, most of all, open to any suggestions and potential improvements from volunteers like me. An unforgettable volunteering position!** ”

Catia Ferreira, BLF volunteer

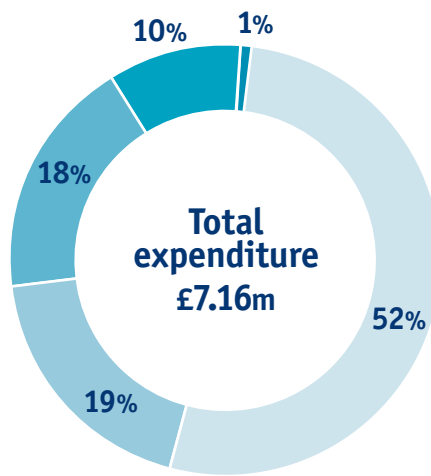
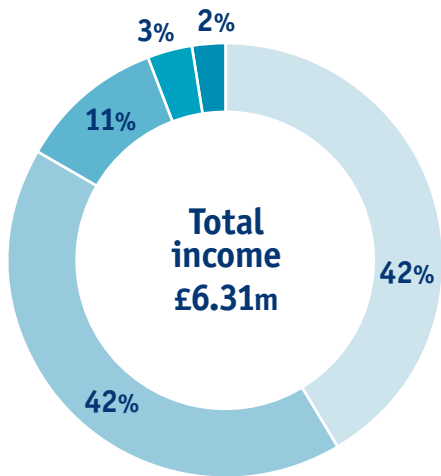
250

Our volunteers contributed 250 hours each week to the BLF.

Finances

All of the life-saving work we do at the British Lung Foundation is funded by our generous supporters. A massive 84 per cent of our money comes from donations and sponsorship from individuals and corporate partners, as well as people leaving us a gift in their will. **This year, our income was £6.13m (2011/12, £6.38m).**

It is vital that we continue to reach even more of the millions of people affected by lung disease, so we keep a close eye on every penny we spend. The generosity of our supporters determines how much we can spend each year in the fight against lung disease. **This year, we spent £7.16m (2011/12, £7.31m)** on research, prevention and support, to help millions of people across the UK.



For every £1 we spend:

81p goes on charitable activity to help beat lung disease.



19p goes towards running the charity.

Income

Legacies	2,582,221
Donations and fundraising	2,539,000
Breathe Easy network, regions and nations	659,894
Service delivery and trading	208,855
Investment income and other	140,601
Total	£6,130,571

Expenditure

Information and support	3,745,253
Fundraising costs	1,347,348
Scientific and medical research (including administration costs)	1,304,728
Campaigning, lobbying and awareness-raising	714,211
Governance costs	44,347
Total:	£7,155,887

This financial summary is taken from our audited statutory financial accounts for the year ended 30 June 2013. You can obtain copies of our financial accounts from our London office or by visiting www.blf.org.uk



Can you help us to help others?

We provide hope and support to hundreds of thousands of people across the UK.

- Our helpline team **gave advice and support to 9,000 people** in 2012/13.
- Our UK network of **240 Breathe Easy groups brings together more than 16,500 people** to share their experiences.
- We provide almost **1 million free information leaflets and booklets** for people affected by lung disease every year.

To continue this life-saving work, and reach even more people, we rely on the generosity of people like you.

Here's how you can help:

- **Make a donation.**
- **Take part in a fundraising event.**
- **Leave a legacy.** Think of the BLF when you make a will and help us to create a better future for people living with lung disease.
- **Remember someone special. Make a donation in honour of a loved one or set up a Breath of Life tribute fund.**

There are lots of different ways you can donate.

For more information on any of these options, give us a call on **020 7078 7941** or visit **www.blf.org.uk/giving**

You can also donate £5 to the British Lung Foundation simply by texting **'LUNGS'** to **70500**.

Matt Green is a keen runner and father of two from Birmingham.

“ My dad was diagnosed with IPF a few years ago, so I wanted to raise money for the BLF and raise awareness of the condition, and do something my dad would be proud of.

I have run a couple of marathons before but I wanted to do something more, so I decided to do seven marathons in seven weeks! I'd never done anything on that scale before.

I thought it would be a good way to keep the profile up by getting local newspapers involved, and keep money coming in over a longer period. Plus I wanted to push myself that extra bit further.

The first marathon was in Northampton in March 2013, and then I did marathons in Brighton, London, Manchester, Milton Keynes, Halstead in Essex and finally Matlock in the Peak District. The Matlock event is not an easy one to finish on!

I had so much support, and not just from close friends and family. I can't believe how many people sponsored me – even people I hadn't seen in years.

They were so generous – one friend donated £250! My final total was £5,600.

I'm quite resilient, but I have to say, 26 miles is a long way to go! All the events were very different. The Milton Keynes event was the hardest, and the atmosphere was amazing in Brighton.

The crowds were just fantastic and having people from the BLF there to support me also really helped. If you're running for a charity it's nice to see the faces you've been communicating with for months beforehand – they always made a big effort to try and be seen in the crowds.

I had lots of people come to cheer me on at the last race. My two boys and my wife came to every event, and when I got to the last one I saw people I didn't even know were coming cheering from the sidelines!

It wasn't until a couple of weeks later when I saw my dad that I really felt, 'that's why I did it'. My dad knows that all this fundraising and effort goes towards research which can't help him now, but it can help others in the future.

”

“ The crowds were just fantastic. ”





Thank you to all our amazing supporters! We wouldn't be able to do any of our research, campaigning or support work without the help of people like you. Whether you ran a marathon, organised a sponsored walk or cheered at one of our events this year, your support will make a real difference to the lives of people with lung disease. To find out how you can get involved and raise money for the BLF, visit www.blf.org.uk/events

Thank you

We could not continue our investment into world-class research, our work to prevent lung disease and our support for the millions of people affected by it without your support. Thank you to the patients, carers, friends and families, volunteers, fundraisers, health care professionals, experts, donors, politicians and celebrities who have supported us in 2012/13.

Fundraisers

To everyone who has raised money for the BLF – thank you.

Chris Knighton and the volunteers at the Mick Knighton Mesothelioma Research Fund, Amanda Evans, Matt Green, Lindsay Raywood and all their friends and family.

Companies and organisations

Air Liquide
Almirall
AstraZeneca
Aviva
Axa
Barclays
Bespak
Boehringer-Ingelheim
BOC
Carlisle Support Services
Chiesi
CLEAR Northern Ireland
Clement Clarke
Dolby Visisol
Exclusive Contract Services
Fisher and Paykel
Gallagher Heath
GlaxoSmithKline

H&V News
Intermedical
Legal & General
Loughborough College
Napp
Novartis
NATAS
Pari Medical
Pfizer
Philips Respironics
Plumbase
Public Health Agency (Northern Ireland)
Pure O2
Resmed
Royal & Sun Alliance
Shield Environmental
Silverdell
Smile
Zurich

Trusts, foundations and statutory supporters

A M Pilkington Charitable Trust
AMW Charitable Trust
Arnold Burton 1998 Charitable Trust
Austin Bailey Trust
Bartlett Taylor Charitable Trust
Benham Charitable Settlement
Buckland Charitable Trust
Cadogan Charity
Charles & Elsie Sykes Trust
Charles Littlewood Hill Trust
Coutts Charitable Trust
Curtis Family Charitable Trust
Department of Health 'Health & Social Care Volunteering Fund'
Douglas Turner Trust
Dunhill Medical Charity
Edward & Dorothy Cadbury Trust

Edith Murphy Foundation
 Eleanor Rathbone Charitable Trust
 G & E Pollitzer Charitable Settlement
 G M Morrison Charitable Trust
 Garfield Weston Foundation
 George Henry Collins Charity
 George John and Sheilah Livanos
 Burgin Family Fund
 Greendale Foundation
 Harris Charitable Trust
 Helen Jean Cope Charity
 Henry Lumley Trust
 Hugh Fraser Foundation
 J & J R Wilson Trust
 James Ellis Charitable Trust
 John Ellerman Foundation
 John Jarrold Trust
 Joicey Trust
 Joseph & Mary Hiley Trust
 Joseph Strong Fraser Trust
 J Reginald Corah Foundation Fund
 JTH Charitable Trust
 King's Fund
 Martin Connell Charitable Trust
 Merchants House of Glasgow
 Michael Cornish Charitable Trust
 Mrs A A Clutterbuck's Charitable Trust
 Mrs M A Black's Charitable Trust
 N M Rothschild and Sons Limited
 Paul Bassham Charitable Trust
 Peacock Charitable Trust
 PF Charitable Trust
 Phyllis Heygate Fund
 R S Brownless Charitable Trust
 Raymond & Blanche Lawson Charitable Trust
 Ronald Miller Foundation
 Rowan Charitable Trust
 Sammermar Trust
 Santander UK Foundation Charitable Trust

Scottish Government
 ShareGift
 Sir James Roll Charitable Trust
 Sir John Sumner's Trust
 Sir Jules Thorn Charitable Trust
 Sir Samuel Scott of Yews Trust
 Souter Charitable Trust
 South Hertfordshire Lodge 6044
 Strathclyde Police Benevolent Fund
 Swire Charitable Trust
 Sylvia Aitken Charitable Trust
 Sylvia Waddilove Foundation UK
 Tyneside Charitable Trust
 Thomas Roberts Trust
 University of Huddersfield
 White Oak Charitable Trust
 William Leech Charity
 William & Christine Eynon Charity
 Wilmcote Charitable Trust
 Zochonis Charitable Trust

And thank you to the Big Lottery Fund



President

Prof Sir Michael Marmot

Chair

Peter Dolphin

Vice-presidents

Greta Barnes MBE
Prof Peter Barnes
Sir Christian Bonington CBE
Lord Borwick of Hawkshead
Prof Mark Britton
Dame Judi Dench CH DBE
Sir Terence English KBE
Prof Duncan Geddes
Baroness Fritchie of Gloucester DBE
Prof Sir Malcolm Green KBE
David Hanger
Prof Sue Hill OBE
Dame Deirdre Hine DBE
Prof Stephen Holgate CBE
Lord Howe of Aberavon CH
Prof William MacNee
Dr John Moore-Gillon
Prof Michael Morgan
Dr Keith Prowse
Richard Reid
Sir Richard Sykes
Lord Tugendhat of Widdington
Prof Lord Turnberg
Prof Dame Margaret Turner-Warwick DBE
Dr Robert Winter

Board of trustees

Prof Stephen Spiro (vice-chair)
Sabah Zubaida (treasurer)
Ralph Bernard CBE
Lord Borwick of Hawkshead
Richard Chappell
Prof Duncan Empey
Dr Patrick Flood Page
David Gill
Richard Pettit
Richard Pinckard
Samantha Prigmore
Dr Gary Ruiz
Prof Stephen Holgate CBE

“ Over the 28 years since its inception, the BLF has grown into one of the most respected healthcare organisations in the country, commanding huge admiration for the quality and impact of its research, campaigning and patient support. At this time of great change in healthcare provision, in a country in which one in five people are affected by lung disease, the work of the BLF has never been more important, and I am greatly looking forward to being a part of that work over the coming years.

Prof Sir Michael Marmot,
President of the BLF



British Lung Foundation

73–75 Goswell Road
London EC1V 7ER

T 020 7688 5555

Helpline **03000 030 555**

enquiries@blf.org.uk

www.blf.org.uk

National offices

Northern Ireland

Tel: 0141 248 0050

Email: northernireland@blf.org.uk

Scotland

Tel: 0141 248 0050

Email: scotland@blf.org.uk

Wales

Tel: 01792 455 764

Email: wales@blf.org.uk