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# Breathing Space

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Issue 26 Autumn 2011

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for BLF  
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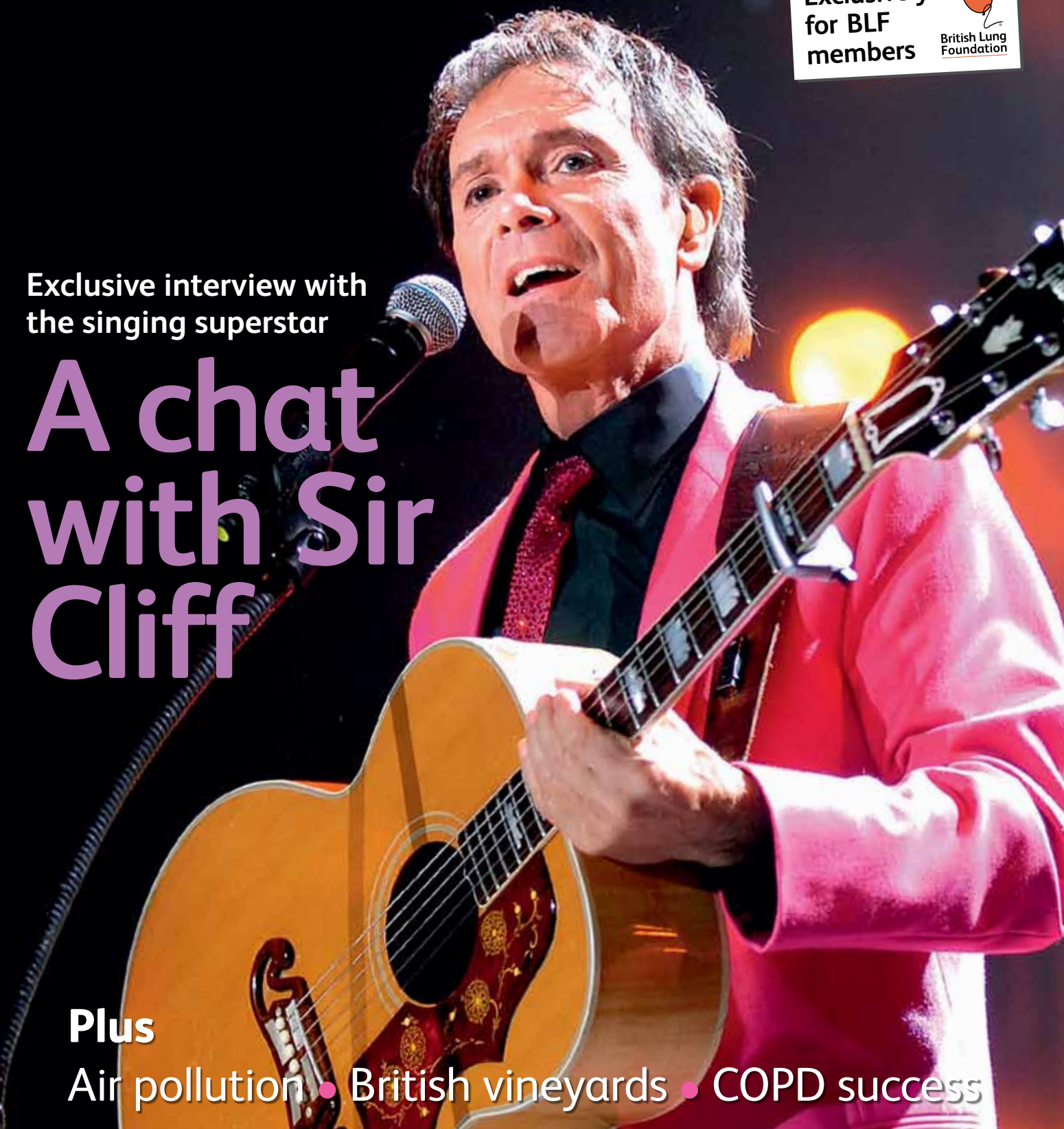


Exclusive interview with  
the singing superstar

## A chat with Sir Cliff

**Plus**

Air pollution • British vineyards • COPD success





# Breath of Life



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A **Breath of Life** tribute fund is a simple and positive way to create a lasting tribute to someone precious – and help overcome lung disease.

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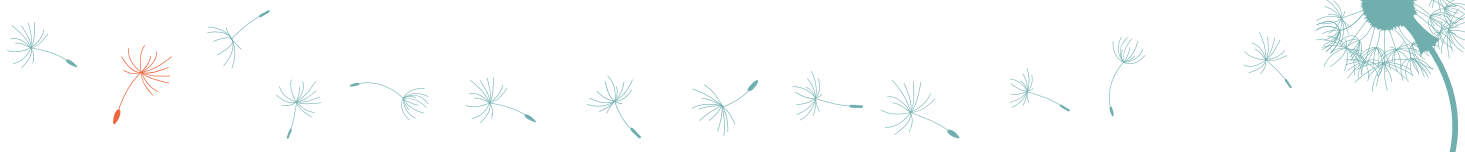


I lost my mum, my aunt and my uncle,  
all within the space of a few years. Their  
loss is indescribable so my family and I  
decided to focus our energies on trying  
to provide some kind of support to other  
people affected by lung disease. It's why  
we set up a *Breath of Life* tribute fund.

Dan Farley, *Breath of Life* tribute fund holder



**British Lung Foundation**





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# Welcome

to the autumn edition of *Breathing Space*



Sometimes the most challenging tasks can also be the most rewarding. The BLF has spent

seven years striving for a national strategy for COPD and asthma in England. The fight wasn't always easy, but now the strategy is here the rewards are set to be significant for people affected by those conditions. Find out more about what the strategy means for you on page 15.

In the third part of our Take care series, on page 12, Philip Thompson talks bravely about the challenges involved in caring for his wife Gwyneth, who has a long-term condition. Their day-to-day life isn't easy, but Philip finds reward in sharing his experience with fellow carers.

Another challenge has been to tackle the devastating diseases caused by exposure to asbestos. On page 22 we reveal how the BLF is investing £3 million in groundbreaking research and awareness raising around asbestos.

Once you've swotted up on policy successes and new research, sit back and read about how singing legend Sir Cliff Richard spends his spare time – then challenge yourself with our puzzles page!

I hope you enjoy the magazine.

*Leonie Brown, Editor*

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### DeVilbiss iGo

The iGo is the smallest of the constant flow units, delivering up to 3lpm or up to 6lpm on a pulse flow. Rechargeable battery giving up to 4.7hrs, includes trolley.

### Sequal Eclipse 3

The latest Eclipse, delivering up to 3lpm constantly or an adjustable pulse flow of up to 6lpm. Rechargeable batteries giving up to 5 hrs, includes trolley

### Invacare SOLO2

Invacare's constant flow unit provides up to 3lpm or up to 5lpm on a pulse flow, Up to 3.5hrs rechargeable battery, includes trolley.

● Battery times quoted at 2lpm

For more information on our range of new and reconditioned units or if you wish to receive information on the new Airsep Focus call us or visit our website



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# Celebrating a new strategy for COPD and asthma



**Dame Helena Shovelton** laments the British summer and looks at the future of lung disease care

**H**aving had such a wonderful spring the summer is proving a bit mixed. Where I am the rain is falling almost every day. All those worries about drought are receding – it's like back in 1976, when as soon as a Minister for Drought was appointed, the heavens opened. The same thing seems to be happening now – a hose pipe ban was announced and then the rain came. I am personally very pleased as it's helping me with some new plantings in the garden, which are now flourishing. My new bed looks great with hydrangeas, lavender and a white climbing rose. My only problem is a wasps' nest in the house's eaves. Gardening is a dangerous occupation!

I'm lucky in that wasp stings don't give me an allergic reaction. My late mother was not so lucky. I still remember when I was a child and she was stung. She swelled up hugely and could hardly breathe. One of us children rang the GP, who said: 'Well, if she isn't dead in 10 minutes, she'll be fine.' She was fine, but it was a very scary 10 minutes.

I am thinking more about the garden and the future as

I am due to retire at the end of June 2012. Over this year I'll be starting some new projects but also trying to ensure everything is in good shape for my successor. It will feel very odd when I reach my retirement point, but I have been extremely fortunate to work in such a forward-looking organisation. Over the year you may have to indulge me if I reminisce a little and think back to when I arrived and the changes that have occurred. Lung disease is certainly higher up the agenda now – but not high enough. So plenty to do yet.

I was delighted to see the *Outcomes Strategy for COPD and Asthma* published in July. You can read more about this on page 15. It is now seven years since this work started and, rather like a child growing up, it has changed many times. So much work has gone into it by so many people. The next challenge is to make sure the strategy is put into action across the country.

It has been a summer of discussion on health and where the NHS should go. From where I sit, the NHS needs to ensure that people with lung disease get the help and treatment they need in the best way possible. I know I am single-minded on lungs, but then would you want me to be anything else?

■ Dame Helena is Chief Executive of the BLF

**GROWING WELL:** Dame Helena's new plantings are flourishing in her garden





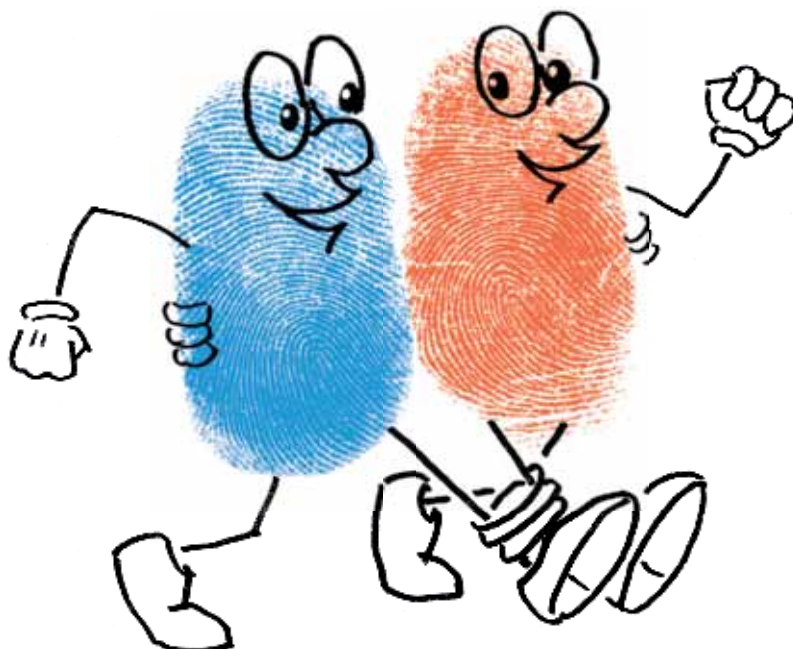
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# news

ALL THE LATEST FROM THE BRITISH LUNG FOUNDATION

**ASBESTOS RISK:**  
Tommy Walsh  
shows his support



## Celebs hammer home the dangers of asbestos

You'll see some exciting famous names campaigning for the British Lung Foundation (BLF) over the next few months...

Dame Judi Dench, *Grand Designs* presenter Kevin McCloud and TV's most popular builder Tommy Walsh are taking part in the BLF's 'Be Asbestos Aware' campaign, which warns

DIYers about the dangers of asbestos when they're getting their hands dirty around the home.

Dame Judi, Kevin and Tommy will be speaking out on behalf of the BLF, drawing attention to the serious risks.

The three celebs have also kindly signed hard hats, which will be auctioned off later this year to raise money for the BLF.

Exposure to asbestos can cause devastating lung diseases, including mesothelioma – an incurable cancer. Nearly 14 million homes were built when asbestos was commonly used. Lots of these still contain asbestos today – which is why this campaign is so important.

'Many people think asbestos is a thing of the past but this hidden killer is still lurking in many British homes,' said BLF Chief Executive Dame Helena Shovelton. 'Before you take a sledge hammer to the wall, or change your boiler, a quick visit to our website will help make sure you're not exposing yourself to danger.'

Tommy Walsh echoed Dame Helena's warning. 'As part of my job I have to know all the tricks of the trade, but one thing I never forget is to protect myself when doing DIY,' he said. 'You should always remember to wear a dust mask that fits your face properly to prevent anything nasty from getting into your lungs.'

■ **Find out more about mesothelioma and how to do DIY safely at [www.lunguk.org/actionmeso](http://www.lunguk.org/actionmeso)**

■ **Turn to page 22 to find out how the BLF is funding research into asbestos-related diseases**

## Media highlights



**Katherine Huntly**  
Press and  
Campaigns  
Manager

### ■ **Breathe Easy Week**

Every year, the BLF campaigns on a particular issue during Breathe Easy Week. This year it was obstructive sleep apnoea (OSA). The team got a host of great coverage on OSA, including articles in *The Daily Mail*, *Scottish Daily Mail* and *The Sun*. Media volunteer Colin Wrighton appeared on Jeremy Vine's BBC Radio 2 show talking about how undiagnosed sleep apnoea caused him to crash his lorry, fatally injuring a motorist.

### ■ **MP's bid to ban smoking in cars**

Alex Cunningham MP tabled a Bill in June calling for smoking to be banned in cars when children are present. The press team secured 19 pieces of coverage on the vote. The Bill has now passed to a second reading on 25 November.





**WORKING TOGETHER:** BE North Staffs members with local health care professionals

## New grant means better support in the West Midlands

**T**hanks to a generous grant from the Big Lottery Fund, the BLF has been able to improve and expand its services for people in the West Midlands.

Part of the grant is being used to fund an exciting new project in partnership with NHS Stoke-on-Trent.

The BLF's regional office is working with the NHS to encourage more people to join their local Breathe Easy (BE) group. BE North Staffs is already growing in numbers thanks to referrals from the NHS's Community Respiratory Team. 'Even at this early stage I can see the work of the project

starting to have excellent results,' said BE North Staffs Secretary Pat Shaw. 'The support we receive from the BLF regional office is absolutely exceptional. I am excited about our plans for the future.'

But that's not all. The grant has funded a new part-time Development Officer to work in the West Midlands. It's also allowed the BLF to give more support to existing BE groups, and support four new groups. It will pay for training events for BE groups in the spring too.

Midlands Support and Development Manager Jeremy Bacon said: 'The additional resource from the Big Lottery has allowed us to do a lot more in the West Midlands. As well as the project in Stoke, we have had the opportunity to increase the contact and support to BE groups across the region.'

## Spread some Christmas cheer by supporting the BLF

We know it's a bit early to mention Christmas, but we don't want you to miss out on the BLF's Christmas concert on Sunday 27 November. It's being held at the beautiful St Clement Danes Church in central London. Mark the start of the festive period with carol singing, listen to the lovely St Clement Danes choir and Christmas readings, then join us for mulled wine and mince pies. Tickets are £15 and will be available

soon (Breath of Life fund holders are entitled to two complimentary tickets). For more details, visit our website [www.lunguk.org/christmasconcert](http://www.lunguk.org/christmasconcert) or call 020 7078 7912.

If you can't make it along to the concert, why not support the BLF by buying our Christmas cards? Take a look at the flyer enclosed in this magazine for more details. Order a catalogue over the phone (020 7078 7941) or check out our

range at [www.blfgifts.com](http://www.blfgifts.com)

If you want to try something different this Christmas, you can buy e-cards to send over the internet at

[www.cardaid.co.uk](http://www.cardaid.co.uk). Don't

forget to select the BLF as the benefiting charity for your order, and we'll receive 30 per cent of the cost of your cards.



## Volunteers' Week

# Celebrating the BLF's brilliant volunteers



**V**olunteers play a very important role in the BLF. That's why the charity was delighted to take part in Volunteers' Week, a national event to celebrate the amazing contribution that the UK's millions of volunteers make to society.

Held in June every year, the event aims to say thank you while raising volunteering's profile and inspiring people to start volunteering.

BLF Chief Executive Dame Helena Shovelton showed her gratitude to BLF volunteers by sending a letter to all Breathe Easy groups. Dame Helena also sent certificates of appreciation to all the people who volunteer in the BLF's offices.

Volunteers from the BLF's head office in London attended a special 'volunteer gathering' with food

**MUCH APPRECIATED:** BLF volunteers from the London office

and drinks. Twenty-five staff and volunteers came along, and Dame Helena presented volunteers with their certificates of appreciation in person. The South West office held a volunteer gathering too. The events were a great success. 'I was really impressed by the BLF's gathering during Volunteers' Week,' said Catherine, a publications volunteer at head office. 'It was clear that a lot of effort had gone into the organisation and there was a great turn out. I was delighted to receive a certificate from Dame Helena!'

■ **Could you volunteer for the BLF?**  
If you want to find out more go to [www.lunguk.org/getinvolved](http://www.lunguk.org/getinvolved)

## Spreading the word about COPD

There are at least 3.7 million people in the UK with chronic obstructive pulmonary disease (COPD), according to research. But an astonishing 2.8 million of these don't realise they have the progressive condition, which could delay crucial treatment.

Spreading the word about COPD couldn't be more vital. Thanks to a generous £32,810 grant from the Pfizer UK Foundation, the BLF was able to run five events to raise awareness this spring at Sandwell Metropolitan Borough Council and housing association Sandwell Homes Ltd in the West Midlands.

Staff came along to find out about the signs and symptoms of COPD, get advice on stopping smoking, and have their lung function tested. An amazing 389 people had lung tests, while almost 80 per cent of attendees left feeling they knew more about COPD and its causes.

## COPD and asthma strategy launched

After seven years of campaigning by the BLF, the Department of Health has launched a new strategy to improve treatment and care for people with asthma and COPD. Published in July, the new Outcomes Strategy sets out six objectives to make sure people with these conditions live as long as possible, with the best quality of life.

■ **Read more about the new strategy on page 15**

# Breathe Easy Week puts obstructive sleep apnoea on the map

**T**his year's Breathe Easy Week was a great success, with groups all over the country working hard to raise awareness of obstructive sleep apnoea (OSA).

From 13-19 June, Breathe Easy (BE) groups nationwide did everything from setting up information stalls at local hospitals and offering lung function testing in shopping centres, to organising quiz nights and cream teas – all to spread the word about OSA, which causes interrupted breathing during sleep, leading to heavy snoring and extreme tiredness during the day.

The week marked the beginning of a long-term project by the British Lung Foundation (BLF) to learn more about the problems patients with OSA face, so the charity can campaign for improvements. During the week the BLF launched the national sleep survey to gather information, asking BE groups to encourage people at their events to take part. The charity also launched an online 'Epworth



test', which people can take to see if there's a chance they could have OSA. More than 6,000 people have now taken the test online.

Here's a round-up of just a few of the things BE groups did to raise awareness of OSA during Breathe Easy Week:

- BE Bath and District had a stand at the Royal United Hospital all week, enthusiastically supported by paralympic athlete and BLF Ambassador Ben Rushgrove. As well as raising awareness of OSA, the group raised a fantastic £500.
- BE Causeway set up a stand with health professionals in Boots in Coleraine, while BE Dumfries asked people to fill in sleep surveys in Loreburne Shopping Centre.

**RAISING AWARENESS:** BE Causeway members at Boots in Coleraine

- BE Grimsby held 'A Week of Hope' with a tombola, book stall, lung function tests, sponsored walk at Cleethorpes, fun day at the Hope Street COPD and Falls Centre and tai chi on the beach.
  - BE South Tyneside set up an awareness stand at Asda supported by the Acute Respiratory Assessment Service from South Tyneside District Hospital.
  - BE Hinckley and Bosworth offered lung function tests to shoppers at the Britannia Shopping Centre.
- A huge thanks to all the BE groups who took part in Breathe Easy Week. We appreciate all your support.

■ Visit [www.lunguk.org/sleep](http://www.lunguk.org/sleep) to find out more about OSA and to take the Epworth test.

Breathe Easy members telling their local community about OSA





## BE groups influencing Welsh politicians

Welsh BE groups had the chance to tell decision-makers about the issues they face and influence change at two exciting events this summer.

BLF Wales organised an event at the Welsh Assembly where BE group members were able to talk face to face with Assembly Members (AM) about the problems affecting people living with lung disease.

Almost 30 AMs attended, including First Minister Carwyn Jones, other ministers from the Welsh Government, and senior

politicians from all the opposition parties.

BE groups also organised a 'Meet the Patients' event in North Wales with the BLF's help. AMs from across north Wales came along, as well as the local MP.

At both events, Breathe Easy members talked about problems like pulmonary rehab, obstructive sleep apnoea, routine lung testing, and services for lung patients in their area. Many of them also echoed the BLF's call for a ban on smoking in cars carrying children.

## News in brief

### Question of breathing

BE Sunderland and local respiratory nurse Ros Rochford recently organised a Question of Breathing event in Sunderland. A panel of experts answered questions about exercise, oxygen and medication from 60 people. The panel included representatives from the BLF, respiratory specialist nurses, respiratory physiotherapists and representatives from Air Liquide, the regional home oxygen supplier.

### Party time

Three new BE groups have launched in London and the South this summer. BE Staplehurst and Haringey have had their first meetings and formed committees. BE Wickford launched in June with a party. The group decked out a hall with balloons and provided a lovely spread of food. Everyone had a good time. Attendees included local councillors and Mike McKevitt, BLF National Services and Development Manager.

## Join Breathe Easy

The Breathe Easy network provides support and information for people affected by a lung condition. Breathe Easy groups meet in many different towns and cities across the UK. They provide an excellent opportunity for people affected by lung disease to meet each other, make friends, and share information and advice. The groups are run by volunteers with the support of BLF staff. Through events like the annual Breathe Easy Week, the network aims to raise awareness of lung disease and campaign for better services. To find out where your local group is and how to join, please contact your regional/national office:

### London and South

73–75 Goswell Road,  
London EC1V 7ER  
t: 020 7688 5555  
e: londonandsouth@  
blf-uk.org

### South West

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e: southwest@blf-uk.org

### Midlands

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e: midlands@blf-uk.org

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### North West

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Liverpool L3 9NG  
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e: northwest@blf-uk.org

“My wife Gwyneth was diagnosed with pulmonary fibrosis – or scarring of the lungs – in December 2008. In her case it’s caused by scleroderma, an autoimmune condition.

Since that first diagnosis, her condition has got steadily worse. In the beginning, Gwyneth’s symptoms – coughing, shortness of breath and tiredness – weren’t too bad, and she could still go out shopping, for example. But that’s not possible now, and she spends most of the day in bed.

#### A TYPICAL DAY

I’ve looked after Gwyneth by myself until recently, when we started getting some help. My typical day can be a little boring, to be honest. It starts early, when I take our dog for a walk. About 9am, I take Gwyneth a cup of tea, a newspaper and her tablets. She gets up briefly to have a wash, but that tends to wipe her out so she goes back to bed for the rest of the morning.

I’ll take her up half a sandwich and some soup for lunch – she has little appetite these days. She might spend the rest of the afternoon reading in bed, before getting up for a small dinner.

On Mondays, Gwyneth does an art class if she feels up to it. On a Wednesday, she might go to day care in a local hospice. That gives me some time to get out and do some shopping. And now on Thursdays, the girls from [carers’ charity] Crossroads come in for three hours to care for her and we have a weekly cleaner too. They can be the only visitors we get all week, and I don’t get out much now.

#### FRUSTRATION

Being a long-term carer is very different to what I’m used to. Being on call 24/7 and not being able to get on and do anything can feel frustrating and restrictive. We have little social life any more.

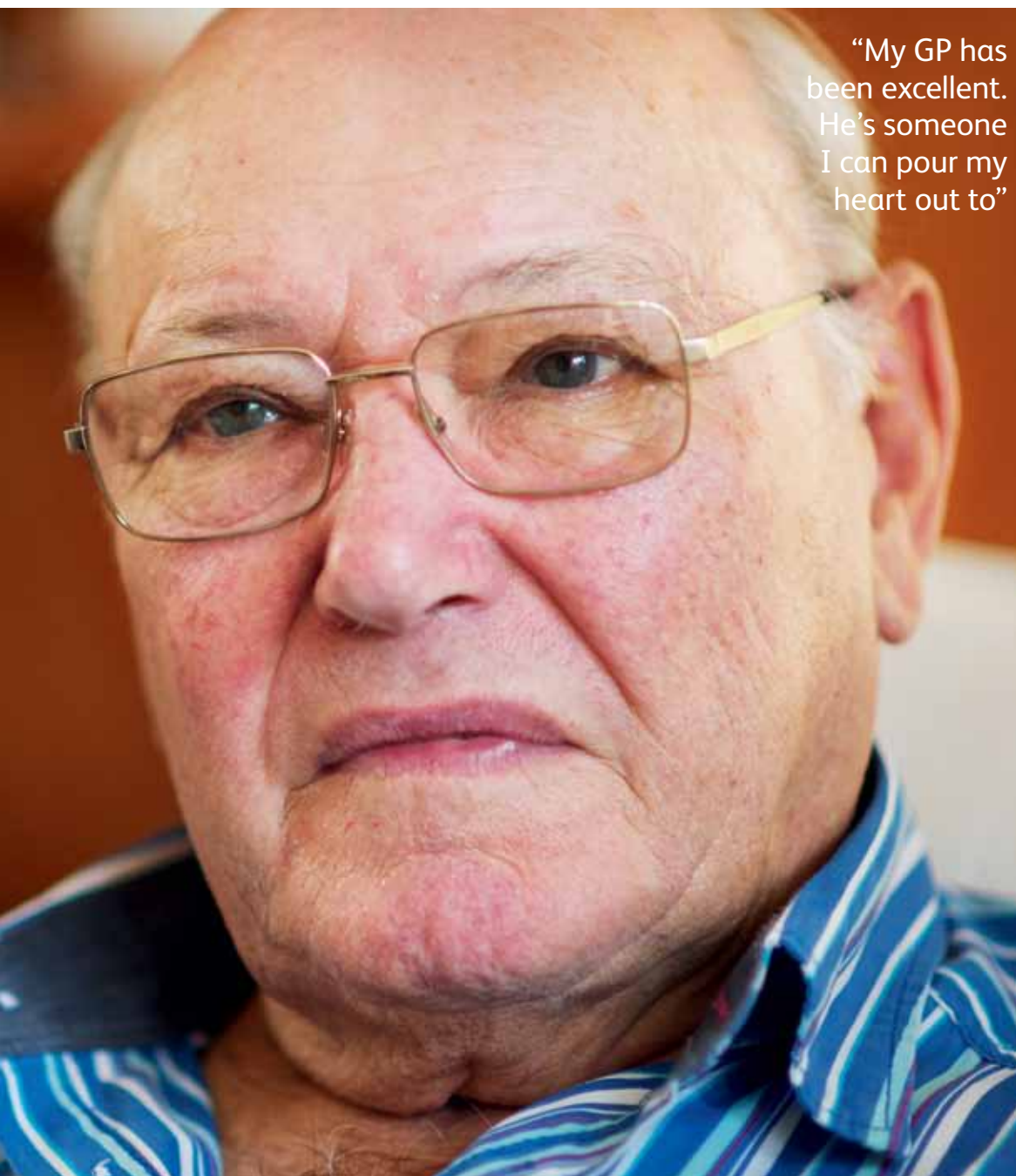
Having the help from Crossroads and the hospice has been great. It gives us both

# Enduring love

Philip Thompson’s wife Gwyneth has a long-term lung condition. In the third of our four-part series on life as a carer, Philip gives a heartfelt account of the challenges, frustrations and rewards involved in looking after her



something to focus on and work towards every week, instead of just being alone all the time. But we had to fight to get it. My GP started the ball rolling for us a few months back, and all sorts of people popped up from social services and other organisations. The local council gave me a Carers Assessment, which all carers are entitled to. We’ve had to press the



“My GP has been excellent. He’s someone I can pour my heart out to”



If you have any questions at all about caring for someone with a lung condition, contact the BLF’s Helpline for advice, information and support. Call on 08458 50 50 20 or email [enquiries@blf-uk.org](mailto:enquiries@blf-uk.org)

The BLF also has a penpals scheme, where the charity will put you in touch with other carers so you can share experiences. Or why not join a BLF Breathe Easy group to meet people in a similar situation to you? There are groups all over the country. Find out about both at [www.lunguk.org/supporting-you](http://www.lunguk.org/supporting-you)

various agencies a few times to get them to sort everything out, but it’s worked out in the end. You have to keep pushing!

However, one thing we’re still fighting for is adequate transport to get to the hospital. We live in Kent, and Gwyneth needs to go to the Royal Brompton Hospital in London every couple of months. I’m 77, and won’t drive to

London at my age. We used to go on the train, but Gwyneth can’t cope with that now. We were offered hospital transport, but that can take hours longer than necessary as one vehicle picks up and drops off several people. Again, Gwyneth can’t cope with that. So we’ve had to resort to using a taxi at £300 a trip. We’re trying to sort this out with the authorities. ➡



### GET HELP

I would recommend that people in my position definitely try to get some professional help. My GP has been excellent. He's someone I can pour my heart out to. When you're entirely alone, it's not easy. He told me to come and see him any time for help or to discuss anything, and so he could check that my health was OK. It's important to look after yourself.

I've also joined my local BLF Breathe Easy group, which is something else to do socially, and it's good to speak to other carers to share what it's like.

Another tip would be not to take anything that the person you're caring for says in the heat of the moment to heart. Being ill is so frustrating for them. Everything is such a struggle for Gwyneth now – she has no energy at all and ends up puffing and panting just trying to do the simplest things. She should be pushing herself to do a bit more exercise, but not being able to breathe properly distresses her. Sometimes she snaps at me out of pure frustration, but then she's fine five minutes later. I've learnt to let it pass over my head because she doesn't mean it. You have to stay relaxed about it.”

■ As told to Jennifer Campbell

■ *In the winter edition of Breathing Space, the final article in the Take care series will look at how best to care for someone with lung disease as they approach the end of their life*



### Caring for someone with a long-term lung condition: advice

If you're caring for someone with a long-term lung condition, here are some tips on coping:

#### Visit your GP

Your GP may be able to refer you on to other services, including the local council or carers' charities, who can organise practical help like cleaning or respite care to lessen your burden. Your GP will also want to know you're a carer so they can monitor your health, and make sure caring isn't getting on top of you. Too many carers don't look after their own health – let your GP help you stay fighting fit.

#### Get a Carers Assessment

All carers are entitled to a 'Carers Assessment' through their local council. This will look at your situation and any extra support you might need. The assessment could lead to the person you care for getting help with anything from personal care to having adaptations made to their home. They could also be offered

respite care for anything from a few hours to a few weeks.

#### Have an emergency plan

Think about who will step into your caring role if there's an emergency and you're unavailable. Social services may be able to help you with this, or you could ask another relative or friend. Some councils provide an 'emergency card' which you can carry around with you. If something happens to you, the card will show you're a carer and who to contact to make sure the person you care for is OK.

#### Make sure you understand treatments

Caring for someone with a long-term lung condition can involve learning about how to administer lots of different treatments. Make sure you're totally clear on how everything works – for example, you can contact your GP surgery or the hospital if you're unsure about when to give medication.



### Where to find care

Whether you have a long-term lung condition yourself or you're a carer looking for some help, there are several places you can turn. Your first port of call should be your local council's social services department. You should be able to speak to someone who will talk you through the options for care in your area and what you're entitled to. BLF Nurses could also help, providing specialist care in

your home. Call our Helpline on **08458 50 50 20** or email **enquiries@blf-uk.org** to find out more. Caring charities can be a source of great support and information too. Many offer care themselves. Some to contact are:

- Crossroads Care: **0845 450 0350**
- The Princess Royal Trust for Carers: **0844 800 4361**
- Carers UK: **020 7378 499**

# Winning the battle

After seven years of campaigning, a new strategy for people with COPD and asthma is finally here – and it promises big improvements, says **Tova Turkel**

**M**ore than three million people in the UK have chronic obstructive pulmonary disease (COPD). Five million live with asthma. Making sure they receive adequate care has been a long-running struggle for the British Lung Foundation (BLF) and the Government. But, with a new national strategy, it's a battle we're starting to win.

After a seven-year fight, led by the BLF, the Department of Health published its *Outcomes Strategy for COPD and Asthma in England* in July, pledging to make much needed improvements for people with these conditions. The strategy acknowledges that COPD and asthma care in England 'falls short', and sets out six objectives to turn this around – making sure patients live as long as possible, with the best quality of life.

Breakthroughs have been made in other parts of the UK too. In Wales the BLF has campaigned for pulmonary rehabilitation services for COPD patients, leading to three new services being introduced where previously there were none. And in



**INFLUENCING:** Dame Helena Shovelton gives her view on the new Outcomes Strategy

Scotland the BLF has campaigned for National Standards for COPD services, supported the development of respiratory managed clinical networks, and led a project to develop remote pulmonary rehabilitation classes across Scotland.

## **GREAT ACHIEVEMENT**

BLF Chief Executive Dame Helena Shovelton feels the strategy in England is a huge step forward. She said: 'We are delighted to welcome the strategy. It will offer improved treatment and care to millions of people suffering with these life threatening and debilitating conditions.'

However, Dame Helena was keen to point out that actions will speak

louder than words. 'To have a real impact, we need to see this strategy put into action across the country,' she said. 'The BLF will continue to work with the Department of Health to ensure this happens, making sure anyone affected by COPD and asthma receives excellent standards of care and treatment – wherever they live.'

## **A CLOSER LOOK**

So, what will the strategy mean in practice for people affected by COPD and asthma?

In brief, it promises early and proper diagnosis, standardised care and treatment throughout a patient's lifetime – no matter where they live, better end of life care and more work to prevent the conditions. ➔

The strategy calls for patients to have more control over their treatment, and for health care professionals to be able to make decisions about how best to treat COPD at a local level. It says: 'One-size-fits all state provision can actually entrench disadvantage and deepen the disparities in service between regions, classes and racial groups in our society. With our plans, people will have the power to drive change in the NHS in their area.'

The strategy also recognises that treating and caring for patients needs to involve many different services and organisations. For example, many people with COPD also have heart disease or depression. The strategy says that different

**"Our clear aim is to ensure decisions are taken locally, with more flexibility for local people to make decisions based on local needs. We want clinicians on the frontline to be supported to deliver what matters to people with COPD and asthma and their carers"** From the strategy

departments should work together to efficiently provide all the services one patient needs. The strategy calls for the NHS, Government, voluntary sector, local authorities and businesses to work more closely to provide all the services patients require.

#### **URGENT NEED FOR IMPROVEMENT**

The need to improve COPD and asthma treatment and care couldn't

be clearer. In the UK, almost double the number of people die prematurely because of COPD than the European average. For asthma, premature deaths are around 50 per cent higher than average.

'It's not right that we lag behind our European counterparts when we are aiming to have the best outcomes in the world,' said Health Secretary Andrew Lansley at the launch of the strategy. 'This is just the start in fundamentally reducing the impact of lung disease on quality of life and life expectancy.'

Poor treatment and care hasn't just impacted on people's health and life expectancy. It's cost the country billions of pounds. Lung disease – particularly that associated with COPD – costs business £3.8 billion in direct costs from lost productivity each year.

Furthermore, at present, COPD is the second most common cause of emergency admission to hospital. If treatment and care was better in general, there wouldn't be so many emergencies, saving money.

#### **OUR SEVEN-YEAR FIGHT**

The BLF's campaign for a national strategy in England, to ensure every person receives a proper diagnosis, standardised care and good support throughout their lifetime, began way back in 2004.

Since then, the BLF has fought tirelessly for the strategy to be

### **Outcomes Strategy for COPD and Asthma: The objectives**

- To improve the respiratory health and well-being of all communities and minimise inequalities between communities.
- To reduce the number of people who develop COPD by ensuring they are aware of the importance of good lung health and well-being, with risk factors understood, avoided or minimised, and to proactively address health inequalities.
- To reduce the number of people with COPD who die prematurely through a proactive approach to early identification, diagnosis and intervention, and proactive care and management at all stages of the disease, with a particular focus on the disadvantaged groups and areas with high prevalence.
- To enhance quality of life for people with COPD, across all social groups, with a positive, enabling, experience of care and support right through to the end of life.
- To ensure that people with COPD, across all social groups, receive safe and effective care, which minimises progression, enhances recovery and promotes independence.
- To ensure that people with asthma, across all social groups, are free of symptoms because of prompt and accurate diagnosis, shared decision making regarding treatment, and on-going support as they self manage their own condition and to reduce need for unscheduled health care and risk of death.



published. Local Breathe Easy groups and BLF members have played an integral role, lobbying their MPs to ask them to fight for the strategy's publication and holding awareness events.

But the BLF didn't make all this noise alone. An external reference group, which patients sat on to share their experiences of living with COPD and asthma, did a remarkable job in pulling out the key problems for patients. This exercise was instrumental in helping the Department of Health set the key objectives for the strategy.

### A HUGE STEP FORWARD

The strategy is not only a huge leap forward for COPD and asthma, but for respiratory disease care in general. The UK has the second highest mortality rate from lung and respiratory disease in Europe. This is a shockingly poor performance,



**PROMISING IMPROVEMENTS:**  
Health Secretary Andrew Lansley  
at the launch of the new strategy

which shows the desperate need for further research, more resources and better services. The Government has stood up, taken notice and is taking action to make sure that everyone living with a lung condition receives good care and treatment. We hope this is the first step towards major progress for all respiratory conditions.

The BLF will be there every step of the way, contributing to making the strategy's objectives a reality. We'll continue screening people for

COPD, BLF Nurses will work with their local NHS to care for patients with lung conditions and countless BLF leaflets will continue to provide vital information for patients, carers and health care professionals, so they can make informed decisions about their treatment and care. Our work is far from done.

■ *Tell us what the strategy means to you. Email [breathing.space@blf-uk.org](mailto:breathing.space@blf-uk.org) or write to us at the address on page 33*

## ➔ What I think of the new strategy



*Sarah Milne is an author and freelance writer. She was diagnosed with COPD in June 2011*

"I'm 40 and have had COPD as a complication of severe asthma since

childhood. I have only been very recently diagnosed, mainly because I just accepted that I couldn't breathe properly and coughed the whole time. I hope others will be diagnosed more quickly in the future.

I like the fact the strategy calls for proactive treatment. I have a poor lung function and am on oxygen but still want to live as active a life as possible and try every treatment possible to stay at home.

My favourite idea in the strategy is giving the patient the role of the 'expert' who will work with their medical team to develop a personalised care plan. I hope this will give me a pathway to follow when I feel infection is brewing so I can arrange to have sputum samples sent and antibiotics prescribed before I end up in A & E.

I also hope that, where an infection calls for IV antibiotics, I'll be able

to self-administer these at home to reduce the time I spend in hospital. The 'expert patient' model is seen in other lung conditions, such as cystic fibrosis, and I think those responsible for implementing this strategy could look there for some good ideas of how it could work in practice."

■ **Sarah writes about living with COPD at [www.coffeeandoxygen.blogspot.com](http://www.coffeeandoxygen.blogspot.com)**

# Investigating interstitial lung disease

From asbestosis to tuberculosis, hundreds of lung conditions fall under the banner of interstitial lung disease. **Dr Rama Vancheeswaran** explains what these disorders have in common, their symptoms – and why precise, early diagnosis is vital when it comes to treating them



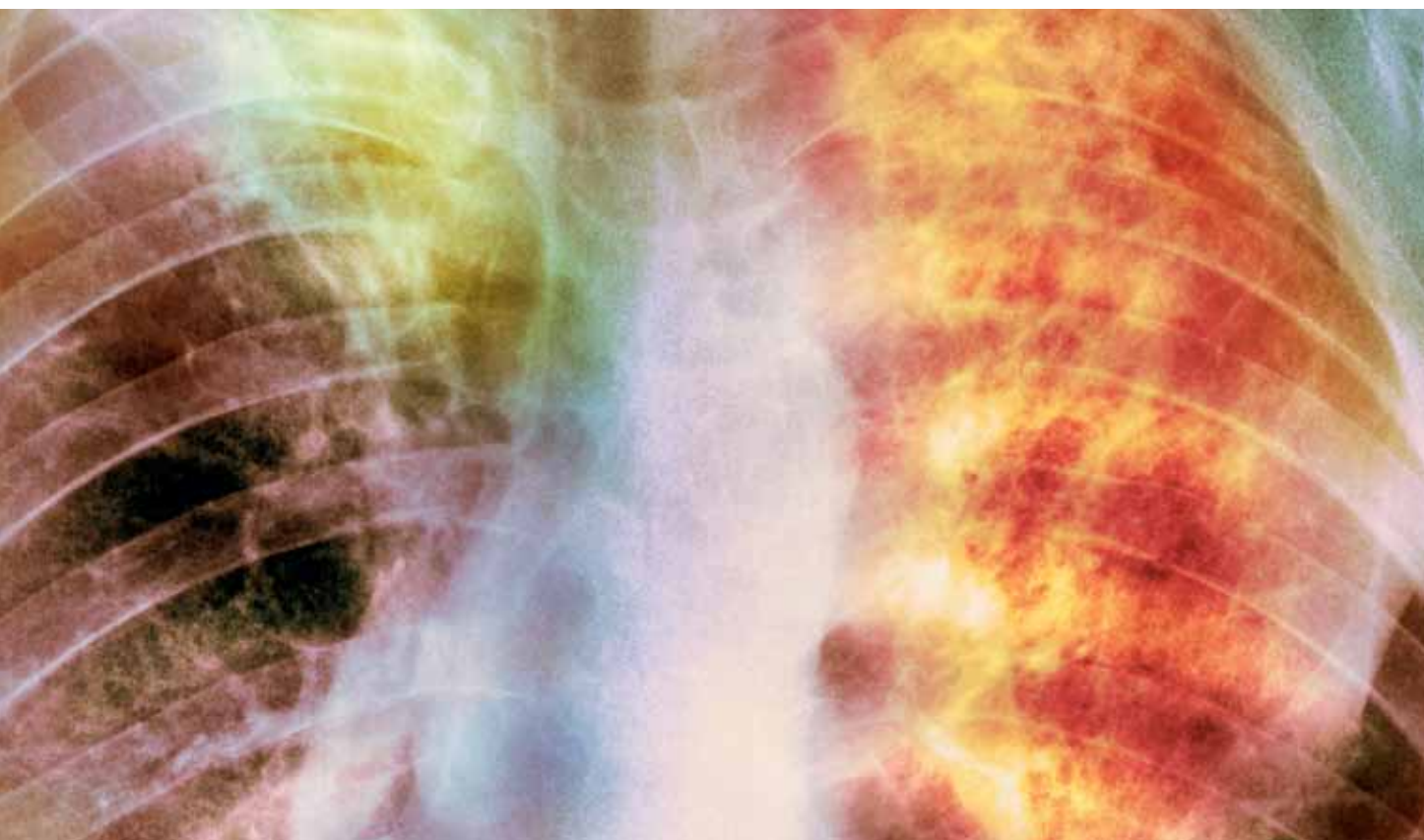
**I**nterstitial lung disease (ILD) is the name for a group of more than 130 lung disorders, all with one thing in common: they cause inflammation and/or scarring of the lung tissue, known as pulmonary fibrosis. As a result, the tissue is filled with extra cells and people can find it difficult to breathe, causing breathlessness and coughing.

Although the symptoms of ILD are very similar, causes and treatments can be very different. Some disorders are fully treatable, particularly if it's possible to work out what's caused them. Diagnosing and classifying the type of ILD early and correctly so it can be treated appropriately is a key challenge for health care professionals.

## TYPES OF ILD

There are many different types of ILD, but broadly speaking, they can be placed into four categories.

- Conditions caused by being exposed to harmful lung toxins such as drugs, smoking, home pollutants or other substances. It is very important to swiftly diagnose this group, as the toxin needs to be removed as soon as possible. Failure to find this toxin may result in continued scar damage to the lung.
- Conditions where the lung disease is part of a whole-body immune disorder (granulomatous disorder) such as sarcoidosis (where an abnormal immune mechanism results in clusters of cells filling the lungs and other organs). Immune suppressants, which stop the immune system malfunctioning, can be very effective in preventing scarring in these cases.
- Conditions where the cause is unknown. (idiopathic).
- Conditions which are associated with whole-body disorders such as scleroderma,



rheumatoid arthritis or lupus. These can also be treated with strong immune suppressants to stop lung scarring.

### HOW IS ILD DIAGNOSED?

A doctor who specialises in ILD is needed to make a proper diagnosis. The doctor must first make sure that the breathlessness and coughing are not symptoms of other problems such as infection, heart disease or other types of lung disease.

Once sure it's ILD, the doctor will start the process of determining the type. Classification is very important to allow accurate treatment. The doctor will begin by taking a very detailed life history from the patient, asking about all medications taken for at least 10 years (prescription and over the counter), exposure to toxins at work and home, hobbies, a full lifetime job history, pet ownership, other symptoms

and medical history. A full set of blood tests looking for toxins or whole body disorders and a lung function test are also needed.

The patient will then have a CT or CAT scan of the chest, which a trained ILD chest radiologist (a doctor who specialises in x-ray images) will examine. Each type of ILD shows a different pattern on this scan, helping diagnosis. Occasionally, doctors will do a biopsy of the lung too. This involves removing a small amount of lung tissue via keyhole surgery for laboratory analysis.

### HOW IS ILD TREATED?

Treatment is different for each type of ILD. For cases caused by harmful toxins (drugs or smoking, for example) the first step is simple: remove the toxin from the patient's environment. This should stop further damage. Occasionally, doctors will also try immune suppression with steroids to reduce

**"A doctor who specialises in ILD is needed to make a proper diagnosis"**





the inflammation and scarring already caused. Most ILD of this kind will be at least treatable, although it may not be curable.

Similarly, ILD found to be part of a whole-body disorder will usually be treatable and reversible, but will need stronger immune suppression drugs.

However, drug treatment for idiopathic pulmonary fibrosis (IPF) is limited. There are ways to manage symptoms, and a lung transplant can cure patients under 65. Some patients don't actually need any treatment as the condition progresses slowly. There are several large drug trials ongoing, run by the IPFnet, which look promising and may provide alternatives for IPF patients in the future.

#### THE FUTURE

Outcomes for patients with this group of disorders are very varied depending on the

**“The earlier and more accurate the diagnosis, the better the chance of reversing the condition”**

type of ILD. Most types of ILDs are treatable, some are curable and IPF can be managed well, although outcomes vary hugely. And with large, global research studies taking place into ILD, treatment can only get better.

Key to improving the lives of people with ILD is ensuring patients understand and are involved in treating and managing their condition. Stopping smoking, exercising and eating healthily can all help. But the most critical aspect of management of ILD is an early and accurate diagnosis. The earlier and more accurate the diagnosis, the better the chance of reversing the condition.

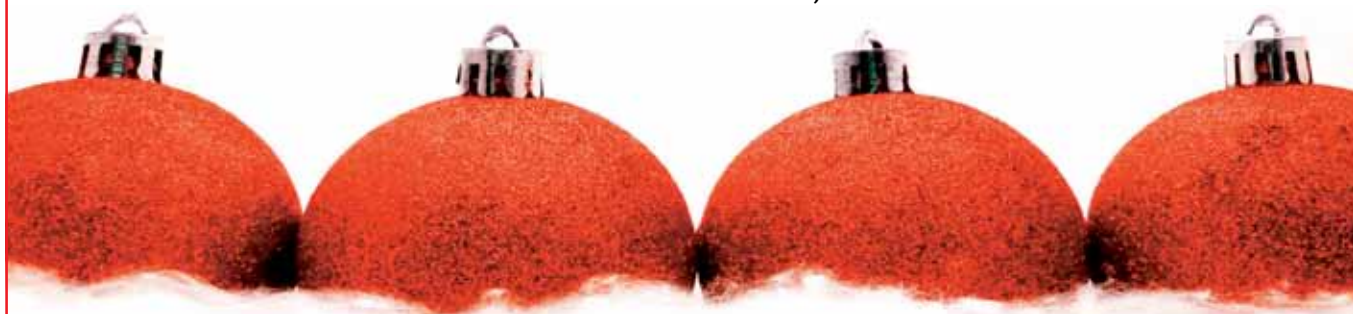
■ *Dr Rama Vancheeswaran is a Consultant Respiratory and Interstitial Lung Disease Physician at Barnet Hospital in London*

■ *For more information on ILD, call our specialists on the BLF Helpline: 08458 50 50 20*

# Christmas Concert

**Sunday 27 November 2011 3pm to 5pm**

**St Clement Danes Church on the Strand, London WC2R 1DH**



Welcome in the festive season with us at the beautiful St Clement Danes Church. Sing carols, listen to the church choir and then join us for mince pies and mulled wine. To book a ticket please call us on **020 7078 7912** or email [events@blf-uk.org](mailto:events@blf-uk.org)

• [www.lunguk.org/christmasconcert](http://www.lunguk.org/christmasconcert)

  
**British Lung Foundation**

# Something in the air

Professor Paul Cullinan explains what air pollution is and the difficulties it can cause for people with lung disease

Our cities may be less smoky these days thanks to factories and homes burning fewer fossil fuels, but air pollution is still a concern in the UK.

So what are the sources of this pollution, and how could it affect your health?

## WHAT CAUSES AIR POLLUTION?

Several substances can cause air pollution:

**Oxides of nitrogen**, which mainly come from motor vehicles. Very high levels can make breathing difficult, but are rarely seen in the air.

**Particles** produced mostly from diesel engines, but also from industry and burning coal and other fossil fuels. You can breathe these into your lungs, and high levels can make breathing problems worse. In vulnerable people, like those with asthma or COPD, or older people with heart disease, these particles can cause heart attacks and strokes.

**Ozone**, which is the chief cause of summer smogs. Levels tend to be highest in the summer and are often higher in the country than in towns. High levels can irritate airways and make breathing difficult for people with lung disease.

**Volatile organic compounds**, which come from motor vehicle fuels. The most significant is benzene, which can cause cancer if you inhale high levels over several years.

**Carbon monoxide**, which comes mainly from traffic fumes – and from smoking. High levels interfere with how the blood carries oxygen around the body, which can affect people with heart disease.

## WHAT HEALTH PROBLEMS DOES AIR POLLUTION CAUSE?

Studies suggest that breathing polluted air can, by a small amount, increase your risk of lung cancer and make children's lungs grow more slowly. Some suggest it may increase

your risk of developing asthma, but this is uncertain.

Some pollutants can irritate airways and cause coughing and shortness of breath, particularly for people with respiratory diseases like asthma and COPD.

## WHAT SHOULD I DO WHEN AIR POLLUTION LEVELS ARE HIGH?

Luckily, UK air pollution doesn't reach levels that mean you have to change your lifestyle to avoid it, for example, by staying indoors.

However, when air pollution is high, adults with COPD and children and adults with asthma may choose not to do so much energetic, outdoor exercise. During these periods it's especially important to keep a reliever inhaler with you if you use one.

■ *Paul Cullinan is Professor of Occupational and Environmental Respiratory Disease at Imperial College London*

## Further information...

These sites offer useful and high-quality information on air pollution in the UK:

- [www.defra.gov.uk/environment/quality/air/air-quality](http://www.defra.gov.uk/environment/quality/air/air-quality)
- <http://comeap.org.uk/>

You can also sign up to free 24-hour email forecasts of air pollution levels in your area from Defra at:

- <http://uk-air.defra.gov.uk/subscribe>

In September, the BLF will publish a new leaflet on air pollution. Look out for it at [www.lunguk.org/publications](http://www.lunguk.org/publications). Once published, you can order a free copy by calling our helpline on **08458 50 50 20** or visiting [blf-gifts.com](http://blf-gifts.com)

# Investing millions to combat asbestos-related disease

The BLF is investing £3 million to fight conditions caused by asbestos.

**Ian Jarrold** looks at the exciting research projects this money will fund

It's been decades since the Government banned asbestos use. But the dangerous material's dark legacy lives on. Today, people exposed to it 20-30 years ago are developing diseases like asbestosis (scarring of lung tissue) and mesothelioma (a cancer of the lining around the

lungs), which claim thousands of lives each year. Treatment for these conditions is too often ineffective and limited. Research into new treatments couldn't be more vital. That's why the BLF is pledging £3 million to tackle asbestos-related disease between 2011 and 2013. While we plan to spend part of this

on raising awareness of asbestos and its dangers, we'll spend the majority on research into the prevention, treatment and cure of asbestos-related disease. Here are just some of the exciting research projects we'll be funding, chosen by a panel of international experts from dozens of exciting applications:

## ➔ Research projects

### ■ Mr John Edwards, University of Sheffield

Is it feasible to use a combined package of different treatments to relieve pain in mesothelioma patients from an early stage of disease?

**Amount awarded:** £24,106

**Duration:** 18 months

John Edwards and his team will investigate whether chest pain caused by mesothelioma can be managed more successfully by combining several pain-relief treatments.

### ■ Dr Brian Huntly, University of Cambridge

Investigating new drugs to treat malignant mesothelioma

**Amount awarded:** £93,156

**Duration:** 36 months

There's evidence suggesting that a protein called GADD34 might be involved in mesothelioma growth. A PhD student working under Dr Huntly will study how GADD34 works and whether interfering with it or related proteins might stop mesothelioma growing.

### ■ Professor Anthony Chalmers, University of Glasgow

Testing the ability of a new drug to increase the effectiveness of radiotherapy in the treatment of malignant mesothelioma

**Amount awarded:** £199,631

**Duration:** 36 months

Success of radiotherapy treatment for mesothelioma is limited. Prof Chalmers will investigate the effectiveness of new drugs, called TRAIL agonists, to make radiotherapy more effective.

### ■ Dr Peter Campbell, Wellcome Trust Sanger Institute, Cambridge

Understanding the genetic causes of mesothelioma

**Amount awarded:** £145,344

**Duration:** 24 months

Asbestos fibres damaging genes in the cells of the lungs causes mesothelioma. Dr Campbell aims to uncover which genes are harmed in this process. Understanding which genes are important could help scientists develop new ways to detect and treat mesothelioma.



■ **Dr David Waugh,  
Queen's University Belfast**

Overcoming resistance to drugs used to treat mesothelioma; development of a novel, effective therapeutic strategy  
**Amount awarded:** £188,020  
**Duration:** 30 months  
 Current chemotherapy drugs for mesothelioma have limited success. Dr Waugh and his team will test new types of drugs called IAP inhibitors, which they believe will increase the effectiveness of existing chemotherapies to fight mesothelioma.

■ **Professor Julian Peto,  
London School of Hygiene and Tropical Medicine**

Current asbestos exposures and resulting mesothelioma risks in the UK population  
**Amount awarded:** £199,743  
**Duration:** 24 months  
 Asbestos is no longer manufactured and used in the UK but is still found in many older buildings. The exact risk this poses is unclear. Professor Peto will carry out a study to estimate future risks, and provide projections for numbers of mesothelioma cases.



**FUTURE OF ASBESTOS:** Prof Julian Peto will benefit from a BLF grant

## “I estimate the risk of asbestos to the public”

**Professor Julian Peto tells us more about his fascinating project, funded by the BLF, to predict how asbestos will affect us in the future**

**What inspired you to research this area?**

I became involved in asbestos research in 1974, when I moved to Oxford to work with Sir Richard Doll, who had shown in 1955 that asbestos causes lung cancer. Our research was initially focused on workers from asbestos factories. But it became clear that workers who used asbestos, particularly in construction, were also

affected. Asbestos use ceased 30 years ago, but the risk remains. My main concern now is to estimate the risk to construction workers and the general population from the asbestos that's still in many older buildings, particularly schools. Measures to control continuing asbestos exposure are likely to be misdirected until we know how extensive it is and who is being exposed.

**How does your study work?**

We're looking at asbestos lung burdens in people

born after asbestos use ceased. We've been doing this by examining lung samples taken from people having collapsed lungs surgically repaired, from many different backgrounds and occupations. This will let us predict the future mesothelioma risk for them, different occupations and the general population.

**What will be the most challenging part of your research?**

The amount of asbestos in young people's lungs is now very much lower than it was when asbestos

products were still being used. Measuring such low levels by electron microscopy is difficult and very expensive. Half of our grant from the BLF will go towards electron microscopy costs.

**Who will be working with you on your research? What will they bring to the project?**

My colleagues Christine Rake, who has been supervising our asbestos studies for the past 12 years, and Clare Gilham, who will help with the statistical analyses. Garry Burdett will be doing the electron microscopy.



# Explore the wonderful world of wine

You don't have to go abroad to find good wine. There are vineyards all over the UK producing tasty tipples. Why not visit one near you for a fascinating day out?

## DENBIES WINE ESTATE

Denbies is the largest vineyard in England, found on the site of a centuries-old farm near Dorking in Surrey. Indoor and outdoor tours are

available, where you'll hear about Denbies' history and taste some produce – look out for their delicious sparkling wine.

**How much:** Tours start from £9.50

**Good to know:** There are two restaurants, a gift shop and a farm shop on site.

**Web:** [www.denbies.co.uk](http://www.denbies.co.uk)

**Tel:** 01306 876616

## HALFPENNY GREEN VINEYARDS

Nestled in the heart of the West Midlands' countryside, Halfpenny Green Vineyards grow a wide variety of grapes, producing many tasty wines. Visit for a tour, to treat yourself to a cream tea in their tea

room or to shop in their craft centre and delicatessen.

**How much:** Halfpenny only offer group tours – for a minimum of 10 people during the day and 20 at night. These cost from £7.50 to £14.95 per person.

**Good to know:** For £35 you can adopt a vine. You'll get to visit your vine with a vineyard tour plus enjoy a meal and bottle of Halfpenny wine.

**Web:** [www.halfpenny-green-vineyards.co.uk](http://www.halfpenny-green-vineyards.co.uk)

**Tel:** 01384 221122

## VINOPOLIS

A good wine tour doesn't have to mean a trip to the countryside. Vinopolis, in London, offers wine tasting five days a week. With wine

from all over the world, your palate is sure to be dazzled!

**How much:** From £21-£38.50.

**Good to know:** Vinopolis also offers spirits and beer tasting, and has

four restaurants and bars where you can continue the fun after you've sampled your wine.

**Web:** [www.vinopolis.co.uk](http://www.vinopolis.co.uk)

**Tel:** 0207 940 8322

## GLYNDWR VINEYARD

Glyndwr Vineyard in the Vale of Glamorgan has been making wine since 1982. Around 6,000 vines produce two white wines, a red, a rose

and a sparkling wine. Wine tasting isn't all they offer though. You'll be able to see llamas roaming the vineyard and gardens too.

**How much:** Tours start from £17.

**Good to know:** There's a bed and breakfast at the vineyard, which costs £60-70 per couple per night.

**Web:** [www.glyndwrvineyard.co.uk](http://www.glyndwrvineyard.co.uk)

**Tel:** 01446 774564

## CAIRN O'MOHR WINERY

Scotland might be better known for its whisky, but wine is made there too. Cairn O'Mohr Winery near Perth shuns grapes in favour of wine made from berries, flowers and leaves. Visit to

sample strawberry and bramble wines, among others.

**How much:** Cairn O'Mohr offers tours and tasting on Wednesdays and Sundays at 2.15pm for £5 per person, from April to October. You

can book group and evening tours out with these times.

**Good to know:** Cairn O'Mohr recently branched out to make cider.

**Web:** [cairnsmohr.homestead.com](http://cairnsmohr.homestead.com)

**Tel:** 01821 642781

# “Tennis keeps my lungs strong!”

Sir Cliff Richard tells us all about his passion for tennis, his new album, and his love of gravy...



## What's keeping you busy at the moment?

I am recording a new Soul Album called *Soulicious* with David Gest, Lamont Dozier, Ashford & Simpson and multiple iconic soul singers.

## How do you stay healthy?

Eat wisely and try to exercise when possible.

## When you consider your health, do you think about your lungs?

Yes I do! However, if I can play an hour of 'practice' tennis and I don't fall over exhausted, I feel sure my lungs are OK!

## What's your party trick?

When in doubt, grab a guitar and sing *Living Doll*.

## What's your pet hate?

Not being able to travel without security checks. They are so time consuming, but necessary, I know.

## What's the best present you've ever been given?

Before cars had automatic locks a fan gave me a key ring with a tiny torch on it – it was a great gift!

## What was the first record you bought?

*In a Persian Market Place* sung by Sammy Davis Jr.

## Can you cook and what's your signature dish?

I can, I believe if you can read, then

you can cook. My signature dish is gravy!

## How do you relax?

Reading is relaxing, but my mind is most relaxed playing tennis... probably because it takes my mind off everything else.

## What is your favourite sport to watch and to play?

Tennis

■ Sir Cliff is a friend of the BLF and The Sir Cliff Richard Charitable Trust has helped to support our research into lung disease.



# Introducing our experts

The BLF's new team of medical advisers will help make sure you get the very best information on lung disease

Whether the BLF is producing leaflets with up-to-the-minute health advice or deciding what stance to take on new government policies, the

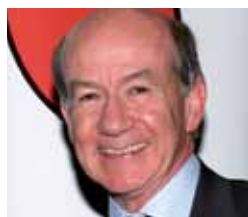
charity depends on the guidance of medical experts. The BLF is delighted to welcome five new medical advisers, who are donating their expertise to help make sure the

charity's information is accurate. Professor Mark Britton, Dr John Moore-Gillon and Dr Keith Prowse are the BLF's new Honorary Medical Advisers. All three are BLF Vice-Presidents too. Professor Warren Lenney will be Honorary Paediatric Adviser, while Chris Fehrenbach is Honorary Nurse Adviser.



**Dr Keith Prowse**

Dr Prowse is a retired Consultant in Respiratory Medicine. He worked at the University Hospital of North Staffordshire, where he helped set up the respiratory unit and medical school. Dr Prowse trained in Birmingham, and spent two years as a Senior Research Fellow in France.



**Dr John Moore-Gillon**

Until recently Dr Moore-Gillon was Consultant Physician in the Department of Respiratory Medicine at Barts and the Royal London Hospitals. He now has a new independent medical practice in London. His special interests include tuberculosis and industrial lung disease.



**Professor Mark Britton**

Prof Britton is Senior Respiratory Consultant at St. Peter's Hospital in Chertsey in Surrey. His special interests include mesothelioma, tuberculosis and asthma. He studied at Barts and the London School of Medicine and Dentistry.



**Professor Warren Lenney**

Prof Lenney took up his post as Consultant Respiratory Paediatrician at the University Hospital of North Staffordshire in 1996. He has particular expertise in asthma, cystic fibrosis, chest infections, bronchiolitis and congenital lung abnormalities.



**Chris Fehrenbach**

Chris started her nursing training aged just 18, when she joined the Royal Air Force. She spent 17 years as Matron for Respiratory Services at Portsmouth Hospital, retiring recently. She was the first nurse ever to be elected to the British Thoracic Society Council.

**"The BLF is vitally important as the only charity representing all forms of lung disease. I'm pleased to help as a medical adviser"**

**Dr Keith Prowse**

**"Over 25 years, I've had numerous roles in the BLF. I relish this wonderful new opportunity to continue working in support of the BLF's vision"**

**Dr John Moore-Gillon**

**"I'm very much looking forward to taking this role on and meeting the BLF Nurses, and giving something back to the profession"**

**Chris Fehrenbach**



## How I work with the BLF

Chris Knighton, founder of the Mick Knighton Mesothelioma Research Fund

“In autumn 2000, my husband Mick was diagnosed with mesothelioma, a lung cancer caused by asbestos. He had been exposed to it in the Navy as a young man. Mick was given six months to live, and died on 19 March 2001. I was devastated, and still am. He was only 59.

Soon after, I launched the Mick Knighton Mesothelioma Research Fund. My initial aim was to raise £100,000 for research. It didn't seem right that the Government wasn't funding research into this terrible disease affecting so many hard working people. I couldn't believe a man so fit and healthy as Mick could be told he had six months to live and there was no treatment or cure. Some people thought I was mad, but I was determined to do it.

The BLF has helped and encouraged me since the very beginning. Just after Mick died, I met up with Bev Wears, the BLF's Support and Development Manager for the North region. That was the start of a long relationship! I've had the BLF's support ever since.

We donate a large part of the money we raise to the BLF, and the charity decides how to use it most effectively to fund mesothelioma research and raise awareness of the disease. That way we know the money is being spent wisely. I'm a lay person member of the BLF Scientific Committee, so I get a say in how it's spent.

It turned out that raising £100,000 was just the start. We reached that target in 2005, thanks to our supporters doing everything from marathons to holding balls. And by 2006 our first research project to make a chemotherapy drug more effective was underway.

By May 2011, we had raised £1 million. We've used this money to help fund four major research studies. These include two studies on how stem cells could help mesothelioma patients, and another into how the drug Alimta can be used effectively. The latest study is looking at how starving mesothelioma cells of nutrients could help fight the disease. We've also set up support groups for people with and affected by mesothelioma.

Now our aim is to raise another £500,000 to set up the UK's first mesothelioma tissue bank through the BLF. This will be a central point for research into the disease. At the moment, there are pockets of research across the country, but the bank would make such a huge impact on research nationally and internationally, saving lives.”

“Some people thought I was mad, but I was determined to do it”



### Further information...

- To find out more about the Mick Knighton Mesothelioma Fund and how you can help raise money for the new tissue bank, go to [www.mickknightonmesorf.org](http://www.mickknightonmesorf.org)

## 'No two patients are the same'

Young medics explain why they chose a career in lung health



**Dr Elspeth Potton**  
Specialist Trainee in  
Respiratory Medicine and  
Wellcome Trust Clinical  
Fellow in the North East  
Thames region

I graduated from Cambridge University Medical School in 2004. Since then I have worked in Cambridge, Nottingham and London. I started to specialise in respiratory disease in 2008.

I initially became interested in respiratory medicine at medical school. I planned to explore this a little further by organising my medical school elective period in Canada. I set off for Toronto to do two placements – one in the emergency department and one in the department of respiratory medicine. However, half way into the placement, medical students

**“It struck me that emerging new infections were likely to continue being a challenge within respiratory medicine”**

were banned from the hospitals as a public health measure – there had been an outbreak of Severe Acute Respiratory Syndrome (SARS).

In Toronto, it struck me that emerging new infections were likely to continue being a challenge within respiratory medicine. I also noticed that the same infection had different effects in different patients; no two were the same.

During my general medical training I enjoyed looking after a wide range of patients with many conditions. I realised that this was something that I wanted to continue throughout my career. Patients with respiratory infections may require treatment that can be monitored in the community, given in hospital or they may need higher levels of support in intensive care. And they may or may not have underlying respiratory conditions.

Tailoring treatment to the individual is both challenging and rewarding. It can only be achieved by working alongside patients themselves, their families and colleagues. I am currently studying for a research degree into the effects of Human Immunodeficiency Virus (HIV) on cells that act to defend the lung against respiratory infections. Patients infected with HIV are more likely to develop respiratory infections than healthy people. I am particularly interested in the effects of HIV on the response to tuberculosis, as the disease remains a significant problem for HIV-infected people.

This research degree will equip me with a huge number of skills and a greater understanding of bacteria and viruses. I hope to combine these skills with my clinical skills, complete my specialist training and then pursue a career focusing on treating patients with respiratory infections.

## Keep fit, eat well

Helping you lead a  
healthy lifestyle

**T**he air is cooler, the leaves are changing colour and the days are becoming shorter. Yes, autumn has arrived. Why not get outside and enjoy that last bit of decent weather before the winter sets in? Take the chance to cook up some healthy autumn food too...

### Eat a Mediterranean diet

Stock up on lots of fruit, vegetables and olive oil...

People who follow a Mediterranean diet, exercise regularly, don't smoke and keep themselves a healthy weight could live up to 15 years longer, according to a new study

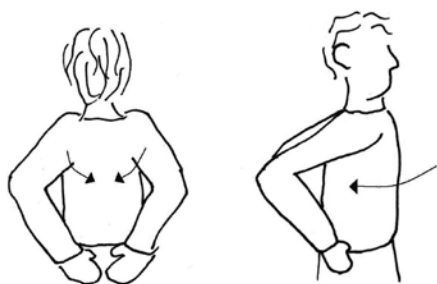




## Chest stretch

**Make sure you're raring to go with this simple stretching exercise...**

Sit up or stand tall. Place your hands on the lower part of your back or hips. Pull your shoulders back and squeeze your elbows together. You should feel a slight stretch in the muscles across your chest.



## Marvellous mushrooms

**Lower temperatures and more rain in autumn does have one benefit: tasty wild mushrooms come into season.**

**You'll be able to buy freshly-picked penny buns, chanterelles and many other varieties from late summer. Or you could forage for your own. You should go out with an experienced**

**guide if you do this: some mushrooms are very poisonous.**

**Packed with Vitamin D and antioxidants, mushrooms are healthy as well as delicious. A bowl of warming mushroom soup is just the thing to ward off autumn's chills.**

■ [www.wildmushroomsonline.co.uk](http://www.wildmushroomsonline.co.uk)

### Mushroom soup

#### You'll need

400g mixed wild mushrooms  
25g dried porcini mushrooms  
200ml crème fraîche  
25g butter  
1 finely chopped onion  
1 sliced garlic clove  
850ml vegetable stock  
Thyme sprigs

#### What to do

■ Put the dried porcini in a bowl, cover it with boiling water, and set aside to use later.

■ Gently fry the onion, garlic and thyme in the butter for five minutes, until soft.

■ Drain the porcini, keeping the stock aside.

■ Add the porcini to the onion, garlic and thyme, and add in the mixed wild mushrooms. Leave to cook for five minutes.

■ Pour the stock in, bring to the boil and simmer for 20 minutes.

■ Stir in the crème fraîche and simmer for a few more minutes.

■ Liquidise the soup in a blender, and strain with a sieve.

■ Try a bowl!

## to live longer, study says

published in the *American Journal of Clinical Nutrition*.

Researchers from Maastricht University found that a diet high in vegetables, olive oil, fruit, nuts, fish and whole grains, with a low intake of meat and alcohol could greatly increase life expectancy.

With the other measures, women could live for up to 15 years longer, while men could increase their lives by eight years.

Prof Piet van den Brandt from Maastricht University said: 'Very few research studies worldwide have analysed the relationship between a combination of lifestyle factors and mortality in this way. This study shows that a healthy lifestyle can lead to significant health benefits.'

■ [www.maastrichtuniversity.nl](http://www.maastrichtuniversity.nl)

# Ask us anything...

Our Helpline experts have the answers to all your lung health and benefits questions

**Q** I have microscopic polyangiitis, causing pulmonary vasculitis. I think this translates as inflammation of the small vascular system in the lungs. I understand that my lungs have 'black holes' and look like those of an emphysema patient. It took seven years to get a diagnosis and I still know very little about the condition. I would welcome any information that you have.



**Sarah Agnew**  
Respiratory Nurse  
on the BLF Helpline

**A** Microscopic polyangiitis (MPA) is a rare autoimmune condition that can affect many different organs

in the body, causing vasculitis (inflammation in the blood vessels).

Vasculitis makes blood vessels narrow to the point of closing off entirely, stopping blood supply. This can mean organs become damaged from loss of oxygen and nutrients supplied by the blood.

The organs most commonly affected by MPA include the kidneys, lungs, nerves, skin and joints. About half of people with MPA have damaged lungs. They can experience shortness of breath, coughing up blood, and/or chest pain. Effects on the lungs can range from mild breathlessness and anaemia (low red blood count) to significant bleeding with profound hypoxia (low oxygen levels).

Some patients will experience several small bleeds in the lungs

over a period of many years. They can then develop fibrosis (scarring) in the parts of the lungs where the bleeding occurred, which can cause many respiratory problems.

We don't know what causes MPA. We do know that it's not a form of cancer, it's not contagious, and it's not genetic – it doesn't usually occur within families. It's diagnosed in the UK in approximately one person per every 100,000 each year. MPA can be very difficult to diagnose, because its signs and symptoms are similar to those of other conditions, such as infections, connective tissue diseases and malignancies.

The usual treatment for MPA is immunosuppressant therapy, usually with steroids like prednisolone and cyclophosphamide initially. A maintenance regime of prednisolone and another immunosuppressant like azathioprine can be used to control the condition.

Long Term Oxygen Therapy (LTOT) for at least 16 hours per day is usually prescribed when MPA patients' oxygen saturations are continuously below 90 per cent and their blood oxygen levels are low.

LTOT is used to make sure vital organs like the kidneys get enough oxygen. When MPA has damaged the lungs, it's important to maintain oxygen levels above 92 per cent when the patient is moving.

**Q** I would like to talk to someone on the Helpline, but I'm worried about the cost of calling. 0845 numbers aren't included in the package I have with my telephone provider.



**Terrel Connor**  
BLF Helpline Officer

**A** It's absolutely OK for you to call us and ask

us to call you back – lots of people do this. Alternatively, email your number to [enquiries@blf-uk.org](mailto:enquiries@blf-uk.org) with a brief outline of what you want to talk to us about, and when it's best to call you – we'll call you straight back if you want. You can also text your number to 07582 289183 and we'll give you a ring.

Please, please, please don't be put off calling the Helpline because of the possible cost!

## Remember

You can call the Helpline any time on

**08458 50 50 20**

[enquiries@blf-uk.org](mailto:enquiries@blf-uk.org)

Many people with MPA who are on LTOT find their oxygen level drops when they're active, although it's fine when they're resting. This is because during physical activity – even something as simple as walking to the bathroom – the body consumes more oxygen. They may need more oxygen during any activity.

If someone with MPA has fibrosis, their lungs will be stiffer than normal, so they have to work harder to breathe in and out. This can make them feel out of breath even if their blood oxygen level is normal. This is why oxygen therapy often doesn't stop them feeling breathless.

Having enough oxygen when moving can help improve tolerance and ability to exercise, but may not stop breathlessness.



**Carol Sheridan**  
Welfare Benefits Adviser on  
the BLF Helpline

**Q I've just been awarded Attendance Allowance. Will this make a difference to other benefits I can get or already receive?**

**A** If you've been awarded Disability Living Allowance (DLA) or Attendance Allowance (AA) you should always check if you're entitled to claim any other benefits. The Government has ruled that people receiving AA or DLA need more to live on than other groups, so you might well have a new claim. AA and DLA are two benefits that don't ever reduce the other benefits you can claim – there's only the possibility of an increase, so don't be worried about enquiring.

**Q I have COPD. I've just tried to put on the central heating, only to find it's not working. As I only receive pension credit, is there any financial support available to fix my heating?**



**Tracey Newton**  
Welfare Benefits Adviser  
on the BLF Helpline

**A** The government-funded initiative Warm Front could help you. It's for people on certain

income-related benefits like pension credit. You could get a grant to improve or fix your heating, insulate your home or replace your boiler.

To check if you're eligible for a grant, go to [www.direct.gov.uk/warmfront](http://www.direct.gov.uk/warmfront) or call 0800 316 2805.

Due to the extreme weather we had last year, Warm Front was inundated with claims and had to close their application process temporarily. If you're interested in the scheme, register as soon as possible to make sure you don't miss out.

Check with your local council whether you're entitled to housing or council tax benefit. Even if you aren't, you may still qualify for a reduction in your council tax if you're awarded AA or DLA – so make sure to let your council know.

Speak to your GP or practice nurse if you haven't done so already to inform them you are providing the main care for your mum.

They should be able to advise you on how to go about getting the flu vaccine to help protect you this winter. It's important to have the flu vaccine each year as the virus changes continually.



**Mark Pilling**  
BLF Helpline Manager

**Q I'm the main carer for my mum who has severe COPD and receives the flu jab. I'm worried what might happen to my mum if I become ill with flu and I am unable to help her. Although I'm not unwell can I still have the flu jab?**

**A** Yes, the NHS recommends that those caring for an elderly or disabled person whose care could be compromised if the carer falls ill should have the seasonal flu vaccine.

- If you have a question for our Helpline experts, email **breathing.space@blf-uk.org** or write to *Breathing Space*, British Lung Foundation, 73-75 Goswell Road, London EC1V 7ER. Names and addresses will be withheld.
- You can contact the Helpline any time for free, impartial and confidential advice by calling **08458 50 50 20** or emailing **enquiries@blf-uk.org**. Lines are open Monday to Friday, 10am-6pm. Calls are charged at a local rate. Advisers will be happy to call you back.



# Have your say

## Breathe Easy

Propped by pillows soft  
Short come breaths  
I see myself looking at and  
through a mirror.

Is that me looking back?  
No – someone I do not know  
Where has that face gone,  
Once full of smiles?

It's here now with me.  
Oh yes, edges blurred,  
But I'm there –  
somewhere.

What will tomorrow's  
mirror reveal?  
Another familiar, blurring,  
shifting, misting free.

A smile revealed –  
A sigh I breathe aloud and  
return that smile.

**NORMA GREENER,  
CHELTENHAM  
BREATHE EASY GROUP  
COMMITTEE MEMBER**

## All a-flutter over device

I was very interested in the  
information provided by  
the helpline experts about  
the flutter device (Ask us  
anything, *Breathing Space*,  
Summer 2011).

About 18 months ago,  
I saw a mention of this

device in your magazine  
and on my next visit to  
the Chest Clinic I told  
my consultant about it.  
He wasn't able to give  
me one, but referred  
me to a physiotherapist.  
She checked me  
out concerning my  
bronchiectasis, explained

how the device worked  
and then gave me one.

I have used my flutter  
every day since. It is much  
more comfortable to use  
than the postural drainage  
and most efficient too! I  
strongly recommend it.

**GEOFF MOORE,  
STOCKPORT**

STAR  
LETTER

## OSA treatment made all the difference

I enjoyed  
reading

the article about  
causes of obstructive  
sleep apnoea in your  
last issue (From tonsils  
to thyroids, *Breathing  
Space*, Summer 2011). I  
was aware I snored from  
my early 20s, but it didn't  
bother me or anyone  
else, although my chronic  
bronchial asthma could  
be a real nuisance.

In the late nineties I  
started to have blackouts.  
Finally I was diagnosed  
with a brain tumour  
which fortunately could  
be removed without the  
need for any follow up.  
However, during the run  
up to the diagnosis I lost  
my job in IT – computers  
do not stand still!

I then started to have  
frequent chest infections

and I was tired all the  
time. I would usually  
collapse at the weekend.  
Repeated antibiotics only  
offered brief respite and  
finally one weekend I  
took myself to the local  
walk-in centre for help. For  
the first time in my life I  
was admitted to hospital  
as a medical emergency,  
put back under a chest  
consultant who added  
bronchiectasis to my list  
of 'problems' and I was  
'sorted out'.

However, my snoring  
was so bad that I  
disturbed everyone else  
on the ward so I acquired  
a sleep consultant who  
diagnosed obstructive  
sleep apnoea! His  
prescription was the  
wonderful CPAP machine,  
which has made a big  
difference.

I have to wonder just  
how many people with  
'chest' problems suffer  
from OSA? If like me they  
are falling asleep all over  
the place, the sooner  
they are sorted out the  
better for them.

**MS CHRISTINE  
ARROWSMITH,  
ROCHDALE**

*Thank you, Christine, for  
sharing your experience  
of OSA. The BLF is  
raising awareness of this  
condition, which can  
cause heavy snoring  
and extreme daytime  
tiredness. If you, or your  
partner, have these  
symptoms, why not find  
out more by taking our  
online sleep test? Find it  
at [www.lunguk.org/sleep](http://www.lunguk.org/sleep)  
– Leonie Brown, Editor,  
*Breathing Space**

## COPD strategy: all talk?

It is all very well the  
Government publishing  
strategy documents –  
these are just pieces of  
paper!

There are already  
government guidelines



**NONIN GO<sub>2</sub>**

atient facing for personal use, the cost effective onin 2 is compact and lightweight with auto on/off and an display.

he 2 is rugged and durable enough to monitor your oxygen saturation levels while exercising, walking, biking and during air travel.

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inc V & elivery. accessories not supplied n stock now

**PROACT**

2 Year Warranty



**NONIN**

ffering professional quality at personal prices the clinician facing onin 9580 offers a tri-colour pulse quality indicator, easy to read and auto on/off feature.

roven onin p 2 technology offers you accurate readings every time.

inc V , elivery & arry ase n stock now

**PROACT**

4 Year Warranty

published by The National Institute for Clinical Excellence for COPD. These claim patients should be supported by a multi-disciplinary team. I have received no such support,

nor have others with COPD to whom I have spoken.  
**MR COUCH, PLYMOUTH**

*What do you think about the COPD strategy? Email or write to let us know.*



### WRITE TO US!

We'd love to hear from you. In the next issue our star letter will win a £25 M&S voucher!

*Breathing Space,*  
73-75 Goswell Road, London EC1V 7ER

[breathing.space@blf-uk.org](mailto:breathing.space@blf-uk.org)

Names and addresses will be withheld on request.  
We reserve the right to edit letters.



## FOR SALE

### PORTABLE CONCENTRATOR

**Make/Model:** SeQual Eclipse 2

**Bought:** July 2008

**Accessories:** Battery charger (mains and car), carry case on wheels, spare cannula

**Comments:** Very seldom used. Fully serviced by Intermedical in May 2011

**Selling price:** £1,200

**Contact:** Christine Moffat

**Tel:** 01463 229821

### PORTABLE GENERATOR

**Make/Model:** SeQual Eclipse 3 with AutoSAT Technology

**Bought:** September 2010

**Accessories:** Battery, power supply and cart, manual

**Comments:** Three years of maintenance with Intermedical included, which will pass to the new owner

**Selling price:** £1,500 or nearest offer

**Contact:** Jane Bird

**Tel:** 01348 811503

### PORTABLE OXYGEN CONCENTRATOR

**Make/Model:** SeQual Eclipse 2

**Bought:** October 2009

**Accessories:** On wheels with telescopic handle. AC mains adaptor, DC adaptor (in car)

**Comments:** Ideal for holiday, travel and exercise

**Selling price:** £1,400 or nearest offer

**Contact:** Mrs S Peck

**Tel:** 07968 828575

### MOBILITY SCOOTER

**Make/Model:** Rascal Liteway 4 Plus

**Bought:** October 2009

**Accessories:** Rain cover

**Comments:** As new. Breaks down for easy transport

**Selling price:** £850

**Contact:** Mrs C Mitchell

**Tel:** 01580 764269

### PORTABLE CONCENTRATOR

**Make/Model:** SeQual Eclipse 3

**Bought:** January 2011

**Accessories:** AC and DC power supply, travel cover case, two batteries, trolley, finger pulse oxymeter

**Comments:** Never used

**Bought:** £3,800.

**Selling price:** £1,500

**Contact:** Mrs P Howell

**Tel:** 07561 314567

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# Puzzles page

Test yourself with our tricky brain teasers

## MISSING LINKS

Find the word that joins two other words to create new words or phrases. Eg: Hand / ? / thing. The answer could be **SOME** to make **HANDSOME** and **SOMETHING**.

AUTUMN / ? / FESTIVAL  
MOUSE / ? / DOOR  
APPLE / ? / HOUSE  
PUMPKIN / ? / CHART  
WOOD / ? / SCREEN

## BACK TO SCHOOL

**English Lit:** In which fictional county is *Tess of the D'Urbervilles* set?

**History:** Which famous explorer circumnavigated the globe in the Golden Hind?

**Geography:** What's Ethiopia's capital?

**Maths:** A glass is full of milk. The total weight is 370g. When the glass is half full it weighs 290g. What is the weight of the glass?

## SUDOKU

Enter digits from 1 to 9 into the blank spaces. Each row, column and 3x3 square must contain one of each digit.

				3	5			2
2			6	9				3
7	9							8
1			2			7		
		5	7					
9						1		
	6			5			9	
	3				6		2	
	2						4	7

## AT THE MOVIES

Name the actor or actress whose jumbled name appears below. We've included one of their films to help you guess!

CLEAN FAIR FIDDLE (Harry Potter)  
ANNOY POSH THINK  
(Silence of the Lambs)  
CRAZED, I MOAN  
(Something about Mary)  
WRONGLY WET PATH  
(Shakespeare in Love)

## ISSUE 25 ANSWERS

### Mixed Up

CELEBRITY  
BERET  
CELERY  
EERILY  
ELECT  
ELITE  
ERECT  
LEERY  
LIBERTY  
LITRE  
REBEL  
RECITE  
RELIC  
TREBLE  
TRIBE  
TRICE

3	6	2	4	5	7	8	1	9
9	4	7	1	8	2	3	5	6
5	1	8	9	6	3	7	2	4
6	7	5	2	4	9	1	8	3
1	8	4	5	3	6	9	7	2
2	3	9	8	7	1	6	4	5
8	2	3	6	1	4	5	9	7
4	5	6	7	9	8	2	3	1
7	9	1	3	2	5	4	6	8

### Creative Cities

BUDAPEST  
EDINBURGH  
ISTANBUL  
TOKYO  
AMSTERDAM  
COPENHAGEN  
BARCELONA  
HELSINKI

apostrophe,  
question mark,  
exclamation  
point, quotation  
marks, brackets,  
parenthesis, braces,  
ellipsis.

### Fast four

1 Period, comma,  
colon, semicolon,  
dash, hyphen,

2 Shoes, socks,  
sandals, sneakers,  
slippers, skis,  
skates, snowshoes,  
stockings, stilts.  
3 Boxing  
4 Dwarf, dwell,  
dwindle.

### CORRECTION

Thank you to the eagle-eyed readers who pointed out that Tokyo is not a European city, as we claimed in the Creative Cities puzzle in the Summer edition. Apologies.

# Breathing Space

AUTUMN 2011/ISSUE 26

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- Manufacturer recommended UK Service & Maintenance centre
- Part-Ex and Buy Back service available to our customers