

BLF Bulletin

The latest news from the British Lung Foundation summer 2018



We plan to make a bigger difference

We want to make a bigger difference to the lives of people with lung disease. To make this happen, we regularly review our plans.

Our updated five-year plan is anchored by key aims:

- To prevent people from getting lung disease.
- To improve people's health and increase life expectancy.
- To improve people's quality of life.
- To be an effective and well-run charity.

We plan to grow our **research** and **policy** work because this will enable us to reach the most people and have the biggest impact.

We will look to increase our investment in **research** to further our understanding of the causes of lung disease and find

better treatments and cures.

We are currently leading the Taskforce for Lung Health to develop a five-year plan to improve the nation's lung health. Our **policy** work will build on this plan so respiratory health is given the priority it deserves, and people have access to the best treatments.

We also continue to provide detailed support and information to people living with all lung conditions through our helpline, Breathe Easy groups and health information.

The voices of those living with lung conditions remain at the heart of what we do.

We'll continue to develop new ways to help people with lung conditions such as our exercise and singing projects.

Find out more about what this new plan means for the evolution of Breathe Easy groups on pages 2-3.

Breathe Easy week: Making a difference in your community



Breathe Easy King's Lynn celebrated Breathe Easy week with four successful awareness days, even securing an article in their local press.

The events were held at two local libraries and at an Asda store. The ten members who volunteered at the venues, educated passers-by on lung conditions and promoted their local Breathe Easy support group. They are sure to have a number of new members at their next Breathe Easy meeting.

Two representatives from their local pulmonary rehabilitation team were also on hand to explain the benefits of PR.

Breathe Easy King's Lynn is now hoping to hold quarterly awareness days at their local library so they can spread their message even further.

Congratulations to all groups who took part in Breathe Easy week 2018 and spread awareness of lung conditions in their community.

Our Living Well Alliance

When you're living with a lung condition it's really important to manage your symptoms so you can have the best quality of life. Our Living Well Alliance partners all offer products, equipment, treatments or services that could help you do this. The partners, Lucas, Pharmacy2U, Actegy, V-Tuf and Insmid, also support our work through generous donations so we can continue to improve people's lives through our research, campaigning and support services. Find out more about the alliance at blf.org.uk/living-well-alliance.



A support group that works for you



We believe that Breathe Easy groups are vital spaces to provide support and information to people living with lung conditions.

That's why we are committed to supporting the groups in all four nations of the UK.

When we reviewed our plan, we listened to what you had to say and reviewed how the groups were operating. Many groups said they wanted greater autonomy and freedom, particularly with regards to their finances. As a result, we recognised the need for the Breathe Easy group model to evolve so groups can run in a way that suits them. That's why all Breathe Easy groups will now have the choice between three models.

We'll be there every step of the way to support your group in their decision.

The three models are:

- **integrated group**, based on the Integrated Breathe Easy (IBE) model. They will continue to have direct support from our team in Liverpool and they will be able to use the BLF brand. They will also have access to a new online virtual learning and support hub to provide support

materials, advice and information. Integrated groups will sign an agreement with the BLF, outlining what the BLF will do for them and what is expected from the group.

- **affiliated group**, run independently but part of the BLF family. This gives groups greater local control. An affiliated brand will be developed for them. They will be able to raise funds for the BLF, local health services and other organisations in order to promote better lung health. They will also have access to our new online virtual learning and support hub. They will agree to broadly support the BLF's aims and principles.

- **independent groups**, independent from the BLF. These groups can choose to continue as a local lung health support group but will no longer be linked with the BLF. Our helpline, health information and other services will always be available to them.

Once you've got the facts, your group will decide which model will work best for you. If your group would like to be one of the first to choose, let your group support officer know. If not, we'll get in touch with you.



A message from Teresa



The BLF is offering groups new opportunities and ways of working. These give our groups choice, more freedom and autonomy.

Over the past ten years, I've really enjoyed being involved in BE groups - I know first-hand the trials and tribulations of running a group. It's not always easy, and I appreciate the time and effort that a lot of people give to their groups.

Every group is different. Each has its own priorities and ways of working.

I know we'll all want to give the options plenty of consideration so we can make the right decision about how our groups will operate in the future.

I'm so proud of what we've achieved over the years. This is now an opportunity to continue to make a difference for our members in a way that works for each group.

I will be working with the BLF during the two years of transition. I want to make sure groups have the right information and support. This will make it easier for each group to take the next step.

I look forward to the development of the virtual learning and support hub and other improvements which I'm sure will make things easier and help groups to run smoothly.

I fully support the plan for change. It's an opportunity for groups to choose the best way to continue to support members, and to make a difference for everyone affected by a lung condition.

Teresa

Secretary, Breathe Easy
Nottingham West and BLF Trustee



Got more questions?

Drop our helpful group support officers an email at breathe.easy@blf.org.uk or give the team a call on **0300 3030 253**.



Q&A

with Petra

Our Breathe Easy manager, answers all your questions.

What happens next?

If your group would like to be one of the first to choose one of the models, get in touch with your group support officer. If not, we'll get in touch with you.

When will my group have to decide?

We plan to start the process in September and for all groups to follow one of the three models by September 2020. Groups will have the opportunity to meet us to discuss the options and criteria to help them decide at a pace that suits them. We'll send you a support pack of information to help you decide.

How will the process work?

Your group support officer will arrange a meeting with you to discuss the options and answer your questions. After this, you choose and the team will support you during the changes.

When will the support packs of information be ready?

These packs will be available by the end of August.

What support will my group get?

The Liverpool team will support each group through the transition. For [integrated groups](#), we'll support volunteers and arrange the transfer to a managed bank account. For [affiliated groups](#), we'll give you guidance on opening a bank account, setting up as a charity and grant applications.

Will groups be able to use the BLF charity number?

Only [integrated groups](#) will continue to use the charity number. If [affiliated groups](#) need a charity

number, we will guide them in setting this up. You will only need a charity number if your group's income is over £5,000 a year.

How will public liability insurance work?

The BLF will continue to provide public liability insurance for [integrated groups](#) and [affiliated groups](#). [Affiliated groups](#) will need to complete an annual review as part of the affiliation agreement.

What about our finances?

We will explain the ins-and-outs of how your finances will work at your meeting with a member of our team.

When will the virtual learning and support hub be ready?

We aim to develop the hub during 2019. We'll consult groups about its content.

How do we find out more?

Give the team a call on **0300 3030 253** or email breathe.easy@blf.org.uk.



A message from John

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I believe these changes will enable us – volunteers – to devote more time to what really matters to us. We want to support people with lung conditions, signpost ways patients can get better care and raise awareness of lung disease and how it changes lives.

BE groups may want to take the opportunity to follow the integrated Breathe Easy model. This means close ties to the BLF, including raising funds to support its vital research, patient

support services and policy work. These groups will have the support of the Liverpool-based team and an online virtual learning and support hub too. They'll be able to use the BLF charity number and brand. The BLF's finance team will run their bank account. This will be a single account for all integrated groups, rather than every group managing their own. This will free groups' treasurers to spend more time on group activities.

The change in emphasis for Breathe Easy can give groups the freedom to support their local NHS respiratory service by becoming an affiliated group. For example by raising funds for equipment that will benefit patients, which isn't permitted under current rules.

If groups chose the new affiliate status, they will benefit from continued support through an online virtual learning and support hub. But they'll no longer need to make quarterly returns to the BLF – and so free up treasurers' time. They'll run their own bank account and have more flexibility in how they use their funds to support people with lung conditions and respiratory services.

Groups can also choose to become independent, and go their own way.

I fully support these changes, and look forward to continuing to work for the benefit of every one with a lung disease.

John

Treasurer, Breathe Easy Basingstoke and District, and BLF Trustee

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Focus on...

Breathe Easy Southsea

Paul Lipscombe is chair of Breathe Easy Southsea. He and Arthur Hamer are the co-founders of the group, which started in 2015.

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Over the years we've worked really hard to promote our group and create strong links with other groups in the area, as well as health care professionals.

We have regular awareness days where we share information about Breathe Easy and lung conditions.

We also know how important it is to manage your condition yourself.

That's why we're passionate about pulmonary rehabilitation (PR). I've experienced the benefits of PR first

hand and know that PR, together with Breathe Easy, have helped me to understand my condition.

Our exercise classes attract about 160 people a week and we're hoping to include even more classes. We're really proud that in the last year we have only had one hospital admission! This is an amazing feat, and proves the benefits of both group support and exercise.

But we don't only exercise!

A number of us are set to go on a summer trip on a canal where we will enjoy a lovely cream tea.

We have great plans for the future and want to increase awareness even more, so watch this space!



BE member honoured by the Queen

Linda McLeod, chair of Breathe East Clackmannanshire, recently received the prestigious British Empire Medal for her incredible support of people living with lung conditions.

Linda is an inspiration. She has COPD but that hasn't stopped her working hard for BE Clackmannanshire, giving anti-smoking talks in schools and campaigning for the BLF.

Linda was diagnosed with COPD in 2004 and has chaired her local Breathe Easy group for eight years.

"Breathe Easy is so important for social interaction, company and something that people look forward to," says Linda. She is also a strong advocate of self-management and believes that people need to be taught to recognise their own signs and symptoms.

But she says it is also important to have links with local health services. That's why, when their group recently had their annual health meeting, they included speakers from NHS 24 and a talk about the 'closer to home' scheme.

When she received the letter informing her that she was being awarded this honour, she was surprised and delighted. "It's so nice to be recognised not only for me but it also brings the Breathe Easy group to the fore," she says.

Linda will officially receive the award later this year from the Lord Lieutenant of Clackmannanshire.



How researcher Louise is hoping to change lives

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Breathing easily is something that most people take for granted. But as you may know, every breath can be a struggle for some people.

To help people who find it difficult to breathe, like those with COPD and IPF, we must find new treatments and drugs. That's why I'm researching the DNA of people with and without IPF and COPD.

I'm wanting to identify if there are differences in DNA which might affect why some people develop IPF

or COPD. Or even why some people get more severe symptoms and end up in hospital and why some don't.

This will tell us who is at higher risk of developing COPD or IPF. It will help doctors provide a clearer diagnosis and know what treatment will work best for each patient.

In the long term, my research will be able to tell doctors and other researchers more about how COPD and IPF progresses. This will help us develop new treatments and drugs for future generations.

It could bring us one step closer to a cure.

Read about why we need to fund more research into lung conditions at blf.org.uk/your-stories.