



breatheeasy

North Staffordshire

SERVING THE COMMUNITY FOR 20 YEARS!





FOREWORD

... AN INTRODUCTION

Twenty years ago, we were still in Europe, Tony Blair was still prime minister and Strictly Come Dancing was aired for the first time. What a long time ago...!

Locally, the significant event was the launching of the Breathe Easy North Staffordshire Community Group! (Honestly! I checked and neither Stoke City nor Port Vale did anything remarkable that season!)

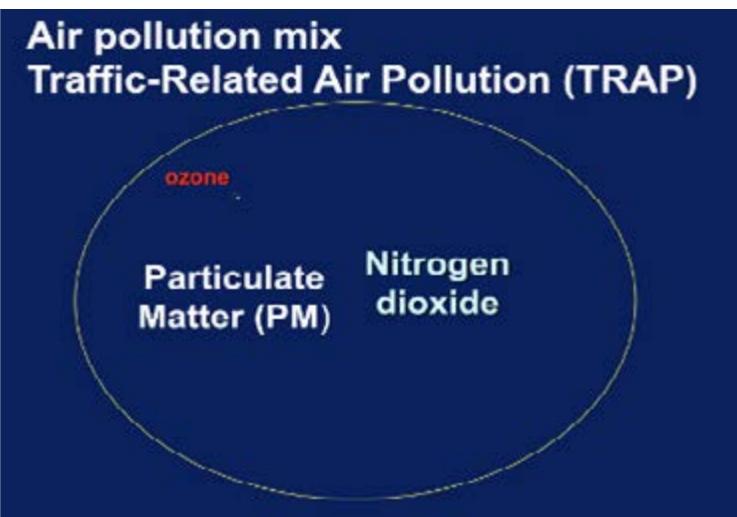
The Breathe Easy group is run by volunteers who, over the years, have helped many hundreds of people with lung conditions as well as their families and carers, providing reliable information and friendly peer support.

This brochure tells their story to celebrate the Breathe Easy groups' 20 years of community engagement in Stoke/Newcastle and North Staffordshire. We want to thank all these volunteers, and recognise all their time and hard work given up for others – it's an amazing achievement! We showcase the activities that the group, together with partner organisations, has done to help so many people feel supported, feel engaged, feel included – and to feel much better!

Victor Cholij February 2024
Chairperson BENS

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1

STOKE & NORTH STAFFS HAVE A PROUD HISTORY

BUT IT'S NOT SO GOOD FOR OUR LUNGS!

North Staffordshire has a proud industrial heritage centred around its world leading Pottery Industry.

This was thanks to the natural resources of clay and coal in the area and the enterprise of such famous people as Josiah Wedgwood. By 1800 North Staffordshire was the most important centre of Pottery Manufacture in the world, creating household names like Wedgwood, Spode, Royal Doulton, Masons, Tams, Aynsley.

Canals were dug in the late 1700s to help this growth through better distribution routes. The level of Industrial activity was such that there were more steam engines here than anywhere else in the UK by 1795! Mainline trains came in 1848 and the substantial Shelton Steel works also started production at this time. By the late 1930s, half of the workforce of Stoke on Trent worked in the Pottery Industry. Indeed, in the 1950's the majority of the workforce worked in Potteries, Coal or Steel Industries.

This success didn't come without problems, however. Pollution from the burning of coal made the city almost permanently in a black smog. This alone was a major cause of lung problems but added to that Coal miners could get "black lung disease" (pneumoconiosis) & pottery workers inhaling silica dust had Silicosis. No surprise that 40% of deaths were from respiratory diseases by the end of the 19th century!

Things started to change in the 1950s. Stoke-on-Trent was the first city council in Britain to get tough under the Clean Air Act, introducing by-laws banning smoky fossil fuels in many neighbourhoods and cracking down on pot banks and other manufacturers responsible for smoke billowing into the heavens. The transformation was incredible – and by the

mid-1960s, clear skies once again dawned over the Potteries.

In addition, the 1970s and 1980s saw the sharp decline in the traditional pottery, mining and steel industries, within the region. Whilst this further significantly helped with air pollution, it created a number of different challenges including pockets of the city where 'joblessness' became particularly high.

Stoke on Trent today is considered one of the Greenest Cities in England, boasting over 100 green spaces. It is very well situated at the centre of the country surrounded by beautiful countryside as well as the industrial heritage. There are excellent transport links (rail and road with the M6/M5 and A50/M1 routes) such that 90% of the UK population is less than 4 hours away!

All this bodes well for the growth and development of Stoke and Newcastle in the future.

On the other hand, these same road links, and the heavy reliance on cars due to a poor bus service, mean that we still have insufficient Air Quality due essentially to vehicle pollution. In fact, we are the 12th worst region for air quality in the UK!

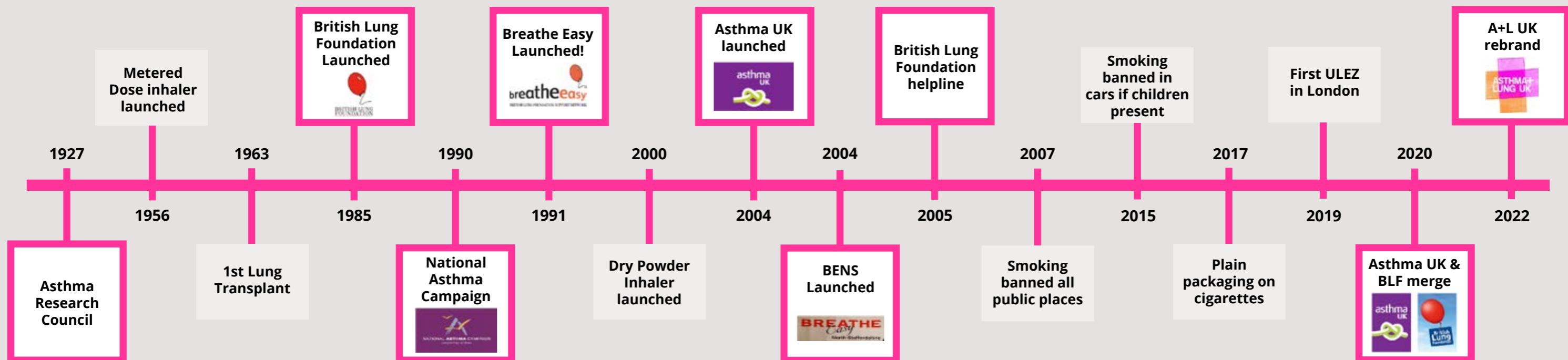
So today the health of residents within the city, when compared with national averages, is still poor. This is as a result of the complex interactions related to the declining economy and previous occupations in mining and steel. Indeed, today we have a 40% higher rate of COPD than the UK average.

So support and action is needed !

ASTHMA & LUNG UK

THE BREATHE EASY PARENT

Breathe Easy North Staffs (BENS) is one of around 150 similar groups around the country. These "Breathe Easy" groups were launched by the British Lung Foundation (BLF) – who today are merged with Asthma UK to create "Asthma + Lung UK."



Asthma + Lung UK are the UK's lung charity fighting for your right to breathe.

The Asthma + Lung UK vision is for a world where everyone has healthy lungs. A world where lung health is prioritised through better understanding, research, treatment and support. They are dedicated to helping create a world where good lung health and the ability to breathe freely are a basic right enjoyed by all. They are the driving force behind the transformation of lung health.

<https://www.asthmaandlung.org.uk/about-us/who-we-are>

The Breathe Easy network, represent the local, face to face support arm of A+LUK.

A+LUK also provide support directly online and through their Helpline:

Telephone Helpline: 0300 222 5800 Speak to a caring expert.

You can talk about anything - from how to manage your condition, to going on holiday.

Email Helpline: helpline@asthmaandlung.org.uk

Patient Forum: <https://healthunlocked.com>

Blog: <https://www.blog.asthmaandlung.org.uk/advice-support>

BREATHE EASY NORTH STAFFS

OUR STORY

The "Breathe Easy North Staffordshire Community Support Group" (to give our full name!) was started in 2004 by *Pat Shaw*, together with the help of *Sue Hope* from the local respiratory clinic. There had been no outside support for patients when Pat's husband had died of pulmonary fibrosis in 2003 and Pat was convinced that more could have been achieved through personal contact with other patients.

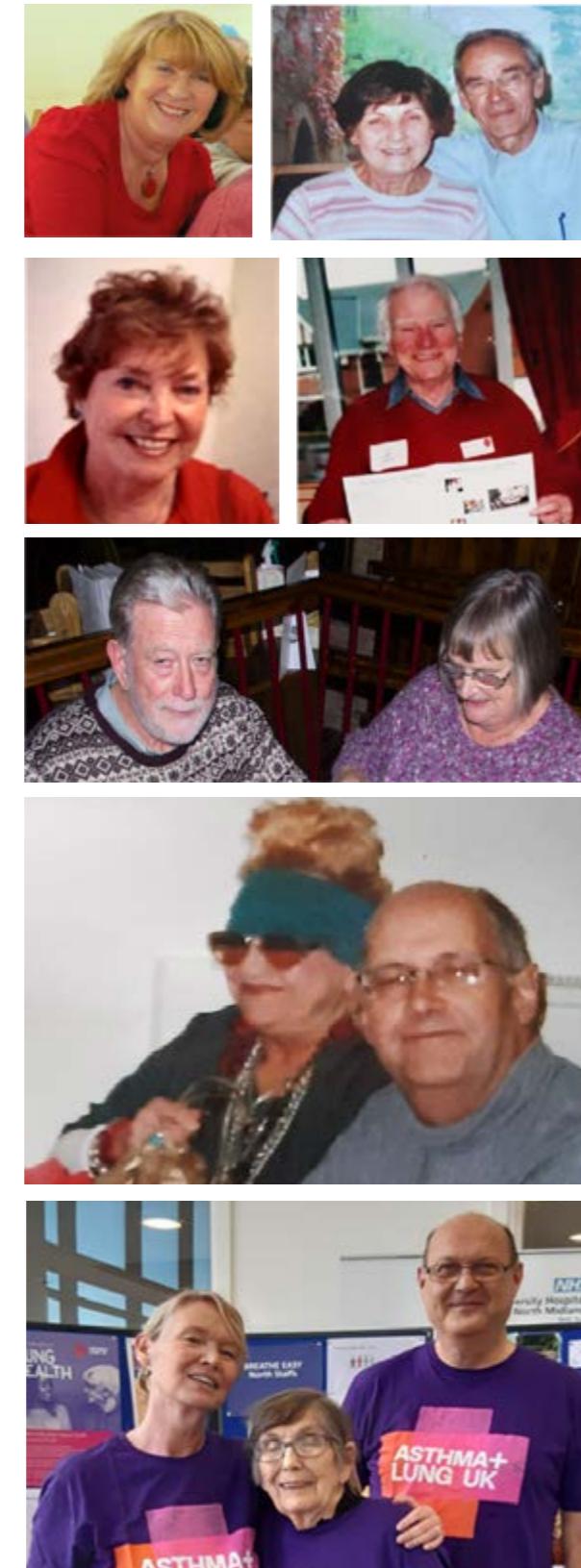
Since the beginning, as well as Pat, people Chairing the group have included *Alan Eaton*, *Keith Sims*, *June Collier*, *Dennis Woolley*, *Hamish Kirkpatrick* and *Victor Cholij* (current Chair). Apologies for any I've forgotten! Some were co-Chairs, whilst others held the post temporarily. The longest serving Chair has been Keith Sims who has been with the group essentially since the beginning!

The group isn't run by the Chairperson alone though and we have to recognise all the work done by the committee members (most often including the spouses of the aforementioned chairpersons!). Indeed, most of the older members of the group have all played a role in committee at one stage or another. Well done and thanks to them all!

Monthly meetings were established, with the same aim as today, for patients and their families to **"make new friends who know what you're going through, and learn more about living with a lung condition".**

The number of attendees has typically ranged between 20 to 40 people – a comfortable, sociable size !

The meeting venues have changed over the years and have included the Royal Stoke Physiology Dept, Hanley Community Fire Station, City Central Library and Trentham. It's always important to consider the space, local transport, available parking, easy access and good tea/coffee facilities!



Today the group meets in the Community Room at Tesco (Clough St, Hanley).

The meetings are on the 1st Friday of each month, starting at 1.30 pm (until up to 4pm).

- There's tea & coffee and cake & biscuits and time for everyone to mingle and chat.
- A respiratory nurse is always present for people to talk to as well. This is a great support.
- There is then usually a qualified speaker (Doctor, Nurse, Pharmacist) on any one of the key topics of Self-Management for lung conditions. This helps ensure that we are all reminded, and kept up to date, on how to have the best quality of life despite our conditions.

1. Understand Your Condition
2. Manage the Environment
3. Take your Medicines
4. Focus on Anti-Infection
5. Manage Breathlessness
6. Exercise
7. Optimize your Diet
8. Have a Positive Mindset/Relaxation
9. Make Regular Medical Reviews
10. Manage other conditions

Occasionally we will have talks on other topics of a community interest (eg life in the Potteries, the Waterways, other local charities like Dougie Mac, Age UK etc). It's good to be in touch with our wider community!

BENS has often published quarterly Newsletters to help inform patients and publicise the group. We still have examples from 2005 and from 2011-2013. These were well regarded – even winning an "Outstanding Newsletter Award" in Dec 2012 from the Breathe Easy Midlands Region!

Technology today makes it easier and so we now publish a monthly newsletter (since Jan 22).



OUR LOCAL PARTNERS

THE COMMUNITY RESPIRATORY TEAM

Breathe Easy North Staffs works in partnership with the Community Respiratory Team (CRT).

This is one of our great strengths! We are natural partners sharing the same aims.

There is a nurse or physiologist specialist from the CRT at all of our regular BENS meetings. This allows any of us to ask questions on anything that might be on our minds – and this is a great support!

This wasn't always the case at the beginning however. The Stoke Community Respiratory Team was only created in 2010 (with Vicky Campbell as Clinical Leader). BENS was there at the launch event!

The community respiratory team (CRT) promote independent living and self-management for people with a respiratory condition through specialist management of the symptom and disease, exacerbation (or "flare-up") avoidance and lifestyle support.

A key element provided by the CRT is Pulmonary Rehabilitation (PR). This is an exercise and education programme designed for people with lung disease who experience symptoms of breathlessness.

It gradually builds up the strength of the muscles surrounding your lungs as well as the strength of your whole body. This in turn helps you feel fitter, stronger and less breathless.

Pulmonary Rehabilitation first started to be offered as a service in Stoke on Trent in 2008.

In 2010 the CRT and BENS collaborated in a study, and pilot activity, looking at "How Support Groups increase patients' ability to Self-Manage". This showed how, working together, we could better improve the health and wellbeing of patients with Lung Conditions. The study was supported by the then BLF and was very successful

Since joining Breathe Easy...

75% said they felt **more confident** in managing their condition

88% indicated they felt **more hopeful** about the future

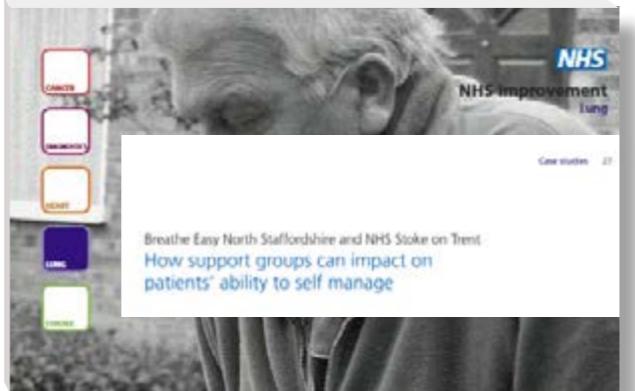
94% said they had a **better understanding** of their lung condition

70% felt they had **more knowledge** of what to do if they become unwell

76% felt they had **more awareness** of the support available to people living with a lung disease

We were published as a Best Practice Case Study in the 2011 NHS Improvement Lungs Report!

We are famous!



This collaborative approach was later studied, and further validated, in a 2016 report from the University of Kent & the BLF, **"THE BENEFITS OF THE BRITISH LUNG FOUNDATION'S INTEGRATED BREATHE EASY VOLUNTARY GROUP NETWORK"**.



The more that Breathe Easy was integrated and supported within the local NHS Trust "Respiratory Pathway" the better the outcome for both the patient (better health, confidence and wellbeing) and the NHS (significant cost benefits).

The same authors of this 2016 "Integrated Breathe Easy" study wrote a further article for the European Respiratory Journal in 2017 – **"Supporting patients self-managing respiratory health: a qualitative study on the impact of the Breathe Easy voluntary group network"**.

They quoted our Stoke study from 2011 as a benchmark and went on to conclude how **"people with respiratory and lung conditions see a social benefit from attending BE groups, as they are able to share their experiences and gain peer support from this social network...BE group members were adapting and transforming their lives to self-manage their condition and, through self-education, to understand their disease."**



So over the years BENS and our local CRT have worked together to pilot and pioneer the collaborative approach that is the benchmark of best practice for the self-management of lung conditions!

There have been many wonderful nurses and exercise physiologists who have come and been with the BENS group at our monthly meetings, giving advice to the members as well as sometimes presenting!

We can't name them all but key people to whom we should give a special shout out to are:

Vicky Campbell, Kevin Greaves, Rebekah Hooker, Isabelle Babin-Cooper (Izzy 'the Oxygen Nurse' as known to many in Staffordshire). And of course our current champion Kelly Brereton!



WE LIKE TO HAVE SOCIAL EVENTS!

FUN TIME TO RELAX.

At least three times a year the group likes to have a day out! This is a great way to get to know each other better and hopefully a good chance to eat well, too! Most of the time, everyone pays their own way for these trips so we don't do anything too extravagant!

In the spring, the tradition is for a Garden Centre visit, preferably with a nice site nearby to walk or visit.

A local favourite is unsurprisingly Trentham Gardens. Others include Bridgemere Gardens and Wolseley Bridge Garden centre (next to the Nature Reserve).

In the summer, the trips are a bit further afield and are more aimed at the coast or a lake. The favourite

here has been Llandudno, but also sometimes closer to home at Rudyard Lake.

At Christmas we have a festive lunch and this is always a highlight – good food and good company!

From time to time the group has had other events away from the usual monthly meeting. These might be a quiz night to raise funds or a visit to the Mayor's parlour to raise awareness (and raise funds, too). We've even hosted a concert with the Newcastle Male Voice Choir to help celebrate the BLF's 25th Anniversary in 2010.



| SOME OF US LIKE TO SING

SINGING HAS BEEN SHOWN TO BE BENEFICIAL TO LUNG HEALTH AS WELL AS GOOD FUN!

Asthma + Lung UK hold a singing group online each week. This was particularly important during the pandemic when people couldn't otherwise gather.

North Staffordshire has always had many "live" choirs which people can join, with a range of different standards and frequency of meeting. This makes singing a really easy activity to get into.

One in particular has been set up specifically to meet our needs:

Village Voices Singing for Lung Health

Village Voices Singing for Lung Health Group started up in Stoke in 2015 as part of a national programme of Singing for Lung Health Groups set up by the BLF (now A+LUK).

The group was set up by Kate Barfield and Greg Stephens who are musicians and choir leaders.

Village Voices meets in the community room at West End Village in Stoke on Monday mornings. Each session involves relaxation, physical and vocal warm ups, breathing exercises and singing, this enables people to feel more in control of their breathing. You don't have to be able to sing, there are no auditions every voice is welcome.

Members of the group have sung as part of theatrical events at the New Vic Theatre, the Mitchell Arts Centre and Bethesda Chapel. This year we stepped into the breach at West End Village when the Christmas panto was cancelled and sang to the residents. We've also had a couple of singing boat trips on the Caldon canal.

For more info email Kate: boatband@yahoo.co.uk

Graduates from Village Voices have gone on to sing with the Stoke City Male Voice Choir and we have a singer at the Daleians! All good fun and very good for your lungs and social networking!



| AWARENESS EVENTS ARE IMPORTANT

PEOPLE NEED TO KNOW WHERE TO FIND SUPPORT!

We've already seen that there is a higher-than-average prevalence of lung conditions here in North Staffs. Indeed, there are an estimated 35 000 people living with poor Lung Conditions in the area.

Many don't know from where to get reliable help. Many others won't even know that they have a condition as the early symptoms can be mild.

This makes it important to us to hold, or participate in, awareness events around North Staffordshire.

Over the years BENS has been active, together with the local respiratory nurses and doctors from the Community Respiratory Team, the Royal Stoke Hospital and indeed from the GP network.

We've been to all the supermarkets, shopping centres (for instance the Potteries & Roebuck), leisure centres and conference centres. Some events have been in libraries, some at the Hospitals and even in church halls!

What we want to do is to reach as many people as possible – patients, their families, and the medical profession.

We've occasionally been on Radio Stoke and in the Sentinel!

The events usually involve posters, leaflets, booklets and even some respiratory testing by the nurses.

You can see from the photos that the events are usually fun too!

Watch out for us especially on these days:

World ASTHMA Day Middle of May (since 1998)

"Love Your Lungs" Week Middle of June (used to be "Breathe Easy Week")

World COPD Day 3rd Wednesday in November (since 2002)

CAMPAIGNING TO MAKE THINGS CHANGE

MAKING OUR VOICES HEARD

Lung disease could be prevented. Lung disease progression and flare ups could be much reduced, for those already with lung conditions. One day, a cure could be found for the diseases.

For this to happen, however, we have to campaign for the right changes to be made.

For instance, we need cleaner air, we need faster & more accurate diagnostics, we need much more medical research.

Did you know that 1 in 5 people are affected by poor lung conditions, and that it is the third biggest cause of death in the UK, yet only 1.8% of government and charity research funding goes into respiratory problems?!

The Breathe Easy priority is to be a support group but as a community group we are also best placed to represent all those with lung conditions. We therefore need to keep ourselves up to date on local and national issues and opportunities, sign petitions for change and engage with our local Mayors, Councillors and MPs. We should also help

inform others in our communities so that they too can put the right pressure on local decision makers.

The best source for our campaign focus is Asthma + Lung UK who are the leaders with active regional and national campaigns.

Breathe Easy North Staffs has indeed over the years been active in informing and campaigning for change. Examples here are

- school awareness event at Baldwin Gate primary (for stopping smoking in cars with children in them)
- Petition hand in to No.10 (for creating a fund to help people move to cleaner transport)
- Parliament Event (for supporting Clean Air actions, for instance Clean Air Zones)
- Local Mayor and MP visits – to lobby for political awareness and support

WE'RE FIGHTING FOR CLEAN AIR



9 | FUNDRAISING AND GIVING

BEING SUSTAINABLE AND PART OF THE COMMUNITY.

Fundraising can be tricky but it can also be fun!

Over the years, BENS has done lots of tombolas, raffles, an auction, a quiz night, a sponsored walk, a Car Club event and even a skydive !! Plus rattled the cans quite a lot (but gently!) at our awareness events.

Importantly though we have also been very fortunate in receiving donations directly from individuals, through legacy (wills and in memorial) and from other local groups (Swimming club, Golden Hill Slimming club, choirs and even a Darts club!). These have been a significant benefit to our finances.

The Breathe Easy North Staffs group is self-financing which means we always have to do a minimum fund-raising to at least meet our running costs (room hire, teas/cookies, speaker expenses, etc).

In addition, we use, and give out, products from Asthma + Lung UK, such as their booklets and leaflets, which we don't have to pay for. Members also benefit a lot from the online resources that are available and occasionally the Helpline. None of these are chargeable. So we should contribute to A+LUK to try to help cover at least some of these costs.

Those are the minimum amounts we have to raise, but when we can raise more there are lots of projects we can run. These could be for more local support, awareness or campaigning! They could also be used to help other local causes that directly impact us and that are in need. There are also the national campaigns from A+LUK that we will want to support for all of our benefit!

BENS has been lucky over the years to be able to meet all of our running costs and indeed we have donated many thousands of pounds to A+LUK.

In addition, to the NHS Trusts our donations have included a chair for the ward, wallet cards for people to carry warning about their conditions and Nebulisers for the wards.

To the community our donations have included gifts to Dougie Mac Hospice, Great Ormond Street, the Guide Dogs and RNLI.

As a community group it is good to help our neighbours as we can!

THANK YOU
TO OUR KIND
SUPPORTERS



WE HELP WITH RESEARCH

PATIENT PARTICIPATION IS VITAL

There are opportunities available to the Breathe Easy group, and to its members, to participate in, and promote, good research into lung health.

This is a really fulfilling activity as you know you are helping make a difference for the future!

As a group:

- We've already seen how, in 2010, BENS helped prove the best way for support groups to work in collaboration with the local NHS respiratory services.
- Further to this, in 2011 BENS contributed to a local NHS project in text reminders and patient monitoring using a system called "Flo" (named after Florence Nightingale)

"It is a text messaging system with a human touch, and has helped to transform the lives of thousands of patients since it was first introduced by a team at NHS Stoke on Trent in 2010."

BENS got an award for our work in this: "Contribution to BLF Projects"

- In 2020 we participated in a Keele University study (published in the British Journal of GPs) on "Breathlessness as an early indicator for COPD". Our key contributor was Keith Sims!



As individuals:

We can participate as "lived experience" members of various studies and medical organisations. Our views and experiences are important to help let researchers and decision makers be aware of our needs and our conditions. Examples of things that BENS members have done:

- Keele University run "Patients as Educator" days to get patients to help train their trainee doctors
- A+LUK run research studies and they recruit COPD patients to help oversee them.
- Our GPs have Patient Participation Groups (PPG) and here we can have a good input to raise awareness as well as improve services

There are also opportunities to participate in Treatment Trials (drugs or other treatments). These are by nature anonymous & confidential – so no examples here! – but they can be found on government websites. It's another way in which we can directly help research.

The image shows two screenshots of the The Health Foundation website. The top screenshot shows a red banner with the text 'Overview of the Florence Simple Telehealth text messaging system'. The bottom screenshot shows a blue banner with the text 'Research' and 'Prognostic value of first-recorded breathlessness for future chronic respiratory and heart disease: a cohort study using a UK national primary care database'.

THE FUTURE

THE NEXT 20 YEARS!

Breathe Easy North Staffs has been an important pillar of support to hundreds of people over the years. This is a fantastic achievement, thanks to the local members and all their hard work volunteering here in North Staffordshire.

We need to build on this success and see if we can do more...

North Staffordshire still has large number of people with lung conditions who we could help.

For these people with lung conditions we want to provide more support through better resources to help with self-management. We need to do this within the community working closely together with the local authorities, NHS and other community groups.

For example, we are starting a weekly exercise class this year specifically aimed at people with lung conditions. This will be a "maintenance" class after they have completed the NHS Pulmonary Rehabilitation course. This is a collaboration between ourselves and Keele University, NHS MPFT, Dougie Mac Wellbeing Centre; supported by a Staffordshire Community grant.

We also need to ensure that everyone with a lung condition knows where to get help. We need to raise awareness and be bold in getting ourselves known!

We want to work towards stopping people having lung conditions in the first place!

For our youth, as well as ourselves, we want to campaign to improve the environment around us especially with Air Quality.

So there is lots we could do!

All of these ambitions will depend of course upon the continued time and support of the volunteers who join our group and the public that donate to us. Thanks to all of you, in advance!

Let's look forward to BENS supporting the community in North Staffs for the next 20 years!

GIVING THE BEST POSSIBLE SUPPORT AND INFORMATION SO PEOPLE CAN STAY WELL

MEMBER QUOTES

HERES WHAT OUR MEMBERS HAVE TO SAY

"From the first time that members met us in Sainsbury's, spreading the word about Respiratory Diseases to the public, my husband had really helpful information re COPD, from both fellow members and professionals.

Breathe Easy always meant, and still means, warmth and lasting friendships. The social side of meetings is vitally important to a lot of people."

"I'm a new member of the group - I've been made more than welcome. What a positive group! Looking forward to an active year"

"We've had good times even when getting wet all day on the trip to Southport!"

"I'm the longest surviving member from when the group first started. I've always enjoyed all the things that we have got involved in and all the help received by talking to other members and the respiratory nurses. Thank you for keeping the group going"

"Pulmonary Rehabilitation saved my life and now Breathe Easy is my life"

"BENS provides a friendly environment of mutual support and fellowship"

"I was very anxious for my husband when he was first diagnosed with COPD. However, coming to BENS and getting to know the fellow members, and learning from the different speakers, has reassured me so much."

"Though a newcomer to the group I have been warmly welcomed and find the group to be a very welcome follow on from the pulmonary rehabilitation exercise group. I believe that both groups have had a positive effect on me both physically and mentally. I feel less isolated within the community due to being able to meet with and socialise with people who share my health problems and understand what it means. Long may it continue!"



Let's talk about

LUNG HEALTH



BREATHE EASY North Staffs

affiliated to A+LUK

Your local Support Group, run by volunteers.

Joining a Support Group could help you manage your lung condition by sharing information and advice, helping you live well, and maybe even reducing the chances of an emergency hospital admission.

We meet on the first Friday each month, 1.30pm

At Tesco Community Room (Inside the store)
Clough St, Hanley, Stoke on Trent, ST1 4LS

For more information contact:

Email: breatheeasy.ns@gmail.com Tel: 0300 222 5800

Web: www.asthmaandlung.org.uk/help/support-network