



## NEWSLETTER June 2024

### ➤ Welcome

We had **18 attendees**, including five new members (welcome Pam, Patrick, Steph, Melissa & Ant!), Vicky from MPFT and our two guest speakers. It was a good crowd! We also had 5 or 6 apologies for Covid-19 (!) or for holidays – we wish them a speedy recovery and/or lots of sunshine! Many thanks to Helen for some lovely cakes!

*Apologies also from our original speaker booked for the topic of Diet and pre-Diabetes - she had to cancel to attend a hospital appointment herself. We'll hopefully be able to see her later in the year.*

Next meeting, Victor will bring a range of Asthma + Lung UK booklets for everyone to look at and to have as needed. This should especially be useful for our newer members, to see what resources are available.

### ❖ **MAIN EVENT: Keele University - Patients as Educators**



**Dr Alison Irvine and Charmaine Estember** from Keele University gave an enthusiastic talk about how we could help the university with the training of tomorrow's doctors.

Medical students need to gain experience in communicating with patients, to learn how to take a holistic view of the patient as real people, not just "cases". The university therefore runs a scheme where the students can interview actual patients to practice both their diagnostic and their patient relationship skills.

The university is looking to recruit patients with COPD to help with this scheme. The patients can include those with mild COPD or with other illnesses too. The interview sessions could be by phone or over the internet (like zoom), lasting for around 45 minutes. Sometimes they could be face to face at the Royal Stoke Hospital or at Keele University. In those cases, refreshments/lunch would be provided as well as taxi fares reimbursed or parking spaces given.

BENS members have contributed to this scheme over the years and say that it is very rewarding to do. We are helping to give a broader, patient centred training for the students.

More information and contact details are in the pamphlet attached to the newsletter.

*Many thanks, Alison & Charmaine!*

## ➤ Other Research opportunities

As people with lung conditions, or close family to people with lung conditions, we can also help with research and with studies aimed at improving the treatment that we all get.

- Asthma + Lung UK coordinate several studies where they want to hear from us as “**lived experience**” contributors. We can help guide and influence the studies by sharing our experiences. We don’t need any formal qualifications or special skills – we just need to be willing to give our point of view on whatever the topic is.

For instance, the study might be about how to ensure we get the right medicines at the right time, and know how to take them. You don’t need to propose the solution, you would just share what experiences you have had and any ideas you have.

Another example might be about how best to get peer support (ie from other patients with your condition) online. Forums already exist but are they what you need? Could they be improved? Some examples of recent topics are listed below.

If you’re interested, please look at the Asthma + Lung UK website:

<https://www.asthmaandlung.org.uk/respiratory-insights/respiratory-voices-network>

or contact Victor to help get you in contact with A+LUK.

*Note that most of these opportunities are run over the internet.*

### Asthma + Lung UK's Respiratory Voices Network

- 7th World Bronchiectasis Conference
  - *A+LUK*
- Supporting children with asthma in a new clinical trial
  - *CARE-UK*
- The struggle of getting your medicine (survey)
  - *Royal Pharmaceutical Society*
- Making asthma research relevant to you
  - *Royal Alexandra Children's Hospital*
- Online peer-support for long-term conditions
  - *Kings College London*
- Discovering new asthma medications
  - *Imperial College London*

- Another option is the **National Institute for Health and Care Research** (NIHR). This is the UK-wide NHS service that helps people find and take part in health and care research across nearly every health condition.

Here you will find many opportunities covering other conditions, and with clinical trials:

<https://bepartofresearch.nihr.ac.uk/>

❖ **BENS X Update:**

The free weekly exercise class has now been up and running since March (with just a couple of missed weeks for Bank Holidays and Easter). There are up to three student tutors each session who are passionate in helping us get fitter and stronger – adapting the exercises to each of us as needed. It's a good workout!

We do aerobic exercises to start with (to help our heart & circulation) and then muscle building exercises to improve our strength and muscle efficiency. This is just like the Pulmonary Rehabilitation programme.

We all know how much we benefit from getting fitter and stronger and how important it is to maintain regular exercise. The BENS X class is a safe environment for us – as we all have a lung condition and the tutors are trained to look out for us. The exercises can be tailored to each person's abilities so we don't have to worry about what level we are to start.

So a class like this should work well for all of us and fit into our regular routines. Indeed, it needs to be done regularly to really have any benefit.

So far only a dozen people have tried the class and half a dozen are regular attendees.

**Don't let this opportunity be missed – it's a positive and active way for us to help ourselves live better!**

❖ **Trentham Gardens Community Day (18<sup>th</sup> May)**



## ❖ August's Summer Boat trips!

The summer outing is a great opportunity to have a relaxing day out in the countryside and socialise to better get to know each other. We can never predict the weather so an activity is a good choice too.

We have TWO outings planned this year as we were evenly split on the vote to choose between them! **Rudyard Lake** on 2<sup>nd</sup> August and the **Beatrice Canal Boat** on 9<sup>th</sup> August.

Both trips are provisionally booked but we will need 12 people for the Canal boat, and at least 12 people for Rudyard Lake, to make them worthwhile. So at the end it depends on how many people actually sign up to do each one. As usual for a social, you can bring family along and you could also do both trips if you liked!

- **By end of June, please let Victor or Hamish know (email, text or phone) which of the trips you'd like to do and for how many people.** As the Canal Boat has a maximum of 12 people, we will prioritise members and then in order of your responses to us. Please also let us know if you aren't joining for either. Thanks.
- **Rudyard Lake:** Friday 2<sup>nd</sup> August



As per last year, the proposal is for a buffet lunch in the room above the café (£10 including teas/cookies) before a choice of the boat trip on the lake (£10? tbc) or train ride along the lakeside (£5.50) or just a walk.

It's a lovely place and Ray (the boat pilot) has a lot of interesting stories about the lake history.

We'd meet at the lake around 12.30 pm for lunch and then aim to take the boat around 2pm for a 45-minute ride around the lake. More teas/cookies available afterwards.

- **Beatrice Canal Boat:** Friday 9<sup>th</sup> August



Based at Cheddleton Flint Mill, the boat has a crew and can **take up to 12 passengers** (including up to 3 wheelchairs) up and down the Caldon Canal.

We can decide which way to go, and for how long (!), but typically the trips would last 3 to 3 ½ hours return. We'll decide the details once we know who's going 😊

We would bring our own lunches – there is a galley with microwave and 'fridge on board. The boat also has an accessible toilet.

The boat hire is £130 for the day, so just over £10 each if the boat is full.

We can decide what time to meet (depending upon the route) starting from 10am or later.

## ❖ The General Election



We've already heard from the Stoke Central Conservative and Labour MP candidates in April. Both were keen to let us know that they wanted to support actions for better lung health – just in different ways (!)

As we get closer to the election date (4<sup>th</sup> July) we will probably be approached by the MP candidates in our own constituencies.

**We need to make sure that they understand that Lung Health is important.**

Is there anything about "Air Quality" in their manifestos, so far?

- **Lib Dems & Greens:** Both propose to introduce a "Clean Air Act"
- **Labour:** Nothing specific
- **Conservative:** No mention, but relaxed road use rules will indirectly INCREASE pollution?!

Here are the four priorities from **Asthma + Lung UK** that you should ask your MP candidate about:

### We're calling on the next government to:



- Commit to and fund a diagnosis target so that no one waits more than six weeks for a lung health diagnostic test, and halve waiting lists for diagnosis
- Commit more funding to medical research, so that life-changing breakthroughs can be made in how we diagnose and treat lung conditions
- **Tackle toxic air pollution by setting out ambitious new clean air laws that protect those most at risk, and fund support to help people make cleaner choices in travelling and heating**
- Stamp out smoking by reintroducing the Tobacco and Vapes Bill as soon as possible

- **Faster Diagnostics**
- **More Research Funding**
- **A Clean Air Act**
- **Re-introduce the anti-Smoking Bill**

For any queries or to find out how you can get involved, email us at [campaigns@asthmaandlung.org.uk](mailto:campaigns@asthmaandlung.org.uk)

**Let's make sure that our voices are heard!**

**Next Get-Together: Friday 5<sup>th</sup> July 2024 – 1.30pm at Tesco, Hanley  
Subject: Mental Wellbeing**

**Contact: Victor CHOLIJ Tel: 07789 713782 or Hamish Kirkpatrick Tel: 07962 400182  
Email: [breatheeasy.ns@gmail.com](mailto:breatheeasy.ns@gmail.com)**

**Have a Wonderful June!**

2024	Main Event	Other Topics	Awareness Events
January	AGM		-
February	MPFT: PR & Exercise		-
March	<b>20th Anniversary Lunch</b>		Blythe Bridge
April	<b>Stoke Central MPs:</b> Lung Health - Future Govt Policy?		Longton
May	<b>Wolseley Centre Nature Reserve</b>		Trentham Gardens
June	<b>Keele Univ:</b> Patients as Educators		Asthma Event: Cannock
July	<b>NHS &amp; Changes:</b> Mental Wellbeing		Meir
August	<b>Day Trip</b>		-
September	First Aid		-
October	<b>A+LUK:</b> Ongoing Research projects		-
November	*tbc		World COPD Day Blythe Bridge
December	<b>Christmas Lunch</b>		-




supporting






**LUNG HEALTH EXERCISE CLASS**  
**"BENS X"**  
**2pm every Monday (except Bank Holidays)**  
*Barlaston Road, ST3 3NZ*

