



Welcome to the 2025 Winter Newsletter

In this Newsletter, you can read about

- Lung Cancer Awareness Month and our All You Need is Lungs campaign
- Conference videos, report and the date of next year's conference
- Kellie Morse's Story
- Brenda Cobb Hardship Fund
- PIF Tick Review Panel
- Our Christmas Appeal
- Members' Survey
- A job opportunity
- Latest news

Lung Cancer Awareness Month

We are again linking up with EGFR Positive UK and the Ruth Strauss Foundation to launch the "All You Need is Lungs" campaign across all our social media channels. The aim of the campaign is to raise awareness that anyone can get lung cancer, irrespective of their age and smoking status. We are very grateful to the members who have volunteered to take part - their stories will have a big impact.

Last year's campaign was nominated for a UK Social Media Award and we would thank everyone who helped make it so impactful. We hope that this year's campaign will be as successful.

The Winter round of Regional Lunches is timed to coincide with Lung Cancer Awareness Month and we hope that as many of our members as possible will be able to attend. We still have areas where there aren't lunches and we would like to hear from anyone who feels that they can help out.

Conference Videos

There were 190 delegates at this year's Annual Conference in September. It was an engaging weekend filled with thought-provoking discussions from some of the leading ALK-positive experts, and inspiring stories.

If you couldn't make it — or if you'd like to revisit some of the sessions — speaker videos are now available to watch on our website.

[Watch the Conference Videos](#)

Save the Date

The provisional date for the 2026 Annual Conference is Friday 25th – Sunday 27th September. The venue is still to be confirmed, as we are exploring suitable venues that can offer good accessibility and facilities at a reasonable price.



In this issue, we feature **Kellie Morse** as our patient story.

Kellie was diagnosed in 2015, before Alectinib and Brigatinib had been approved.

She has now been taking Alectinib for 7 years.

Kellie has a wonderful positive attitude.

[Read Kellie's Story](#)

Brenda Cobb Hardship Fund

Since launching the fund at the September conference, we have made two grants. The fund offers grants to help members with a variety of needs, including travel to attend regional lunches. Please visit our [website](#) for more information about the fund and how to apply for a grant.



PIF TICK Review Panel

In 2023, the Patient Information Forum (PIF) awarded the charity Creator of Trusted Information status. The award is recognised by health information professionals. We had to show evidence that we have a rigorous procedure in place to ensure that all the health information we produce is accurate and easy to read. The procedure requires that each document is reviewed by patients, a carers and an expert. We can add a PIF Tick to documents that have been through this procedure

We're looking for volunteers, both patients and carers, to join a PIF TICK Review Panel. We don't envisage this being an onerous role as we would not anticipate that members will be asked to review more than one document a year.

If you are interested in joining the panel, please email by clicking below. We're particularly keen to hear from seldom heard minority groups, as your perspectives help us make sure everyone's voice is represented in the resources we create. Several of our members have already reviewed documents and they are very welcome to join the panel.

[PIF Tick Panel](#)



Christmas Appeal

Our first Christmas Appeal will be held in the first week of December.

For 1 week only, all donations that we receive will be match funded. We have secured two donors who will match every donation that we receive.

We don't often make appeals directly to our members but this is an opportunity too good to miss.

There is time to think about what you could do to raise funds. How about this for a starter - arrange a dinner party and charge your guests. Now, isn't that a great way to raise funds whilst enjoying the company of friends.

More information will be provided closer to the date.

Patient Preference Study

A pharmaceutical company has asked for our assistance in conducting a study into what factors are important to newly diagnosed ALK+ patients when their first line treatment is being considered.

The study will be open to all patients (or their carers), irrespective of when they were diagnosed.

We will shortly be providing a link to the survey and would ask everyone to participate.

We're Hiring!

Our team is growing, and we're looking to appoint a **Finance Assistant** to record all financial transactions, accurately and timely and to prepare financial reports. Experience in using accounting software is desirable. The hours are flexible, working from home for about 5 hours a week. Please click below if you or someone you know might be interested.

[Finance Assistant](#)

Latest News

We have added a Latest News page to the website which can be accessed from the Home page. We will regularly update the page.

[Latest News](#)

Thank you for reading. We appreciate your continued support and look forward to sharing more updates and opportunities with you soon. If you have any questions or would like to get involved, please don't hesitate to contact us. Your feedback is always appreciated.

Deb

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