thymicUK 2025

A YEAR FOCUSED ON AMPLIFYING THE PATIENTS' VOICE

We are pleased to present an overview of our charity's activities in 2025, highlighting key initiatives, events, and collaborations, which helped us to put the patient voice on the agenda.

2025 Annual Meeting of the British Thoracic Oncology Group (BTOG)

The annual BTOG conference was held in Belfast again, this year from March 3rd to 5th. Marrika was able to represent ThymicUK at the patient advocacy meeting and the wider conference which was a valuable opportunity for learning and networking with the lung thoracic oncology community (with over 1000 delegates).

After 2024's designated session for thymic cancers, this year's main source of interest came from the poster presentations. Five posters concerned thymic tumours, their diagnosis, management, treatment and follow up. For more information and summaries of 3 key posters, please see the News section on our website. Following the presentation of a successful ThymicUK research poster at BTOG 2023, we are interested in ideas for future patient-focused research posters you'd like to see.

International Thymic Malignancies Awareness Month (4th edition)

May was our 4th edition of the annual International Thymic Malignancies Awareness Month in collaboration with the International Thymic Malignancy Interest Group (ITMIG). A dedicated series of webinars increased the awareness and understanding of these rare cancers, not only amongst patients and their families, but medical professionals. ThymicUK contributed a Patient Webinar (more details in the next section). Recordings of all Awareness Months' webinars can be accessed via the ITMIG website. We are already planning the 2026 Awareness Month and welcome your ideas for topics and fundraisers / awareness campaigns.

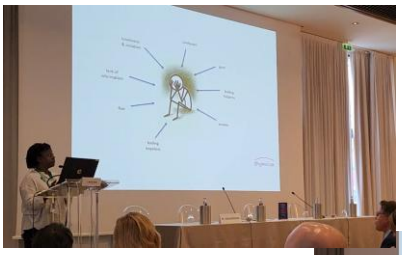
Patient Webinars and Socials

In May, ThymicUK organised a Patient Webinar on the topic of 'Autoimmune Conditions Associated with Thymoma - Their Frequency and Relevance' presented by Consultant Neurologist and Associate Professor at University of Oxford M. Isabel Leite. A recording is available in the News section on our website and via the ITMIG website. In December we hosted a XMAS Social, including a round-up of the year, a sharing of stories from attendees and a look into 2026.

2025 Annual Meeting of the International Thymic Malignancy Interest Group (ITMIG)

In October, Karen, Heidrun and Marrika participated in the annual ITMIG conference. Held in Milan, Italy, this was the first time we were able to attend in person which helped bring to life their first ever patient representative session.

Chaired by ITMIG's outgoing president Malgorzata Szolkowska, whose dedication and support we are very grateful for, the session was titled 'Hear the Patient Voice', and we presented directly to thymic focused clinicians from all over the world. Together with TUTOR Tumori (Italy) and a patient from the Czech Republic, ThymicUK highlighted the key value of patient support groups (Laura spoke about Tutor Tumori, followed by Karen who shared the story of ThymicUK and what led her to start the group), the value of a dedicated Thymic nurse (Marrika from ThymicUK) and we ended with a patient (Dagmar, from Czech Republic) sharing her story and challenges in a place that doesn't yet have any local systems of support.



Prior to the conference, we invited delegates to fill in a short survey to help us better understand their current awareness of, use of, and thoughts about patient support groups / materials, etc. The results will guide us in developing the thymic patient community. We are taking this initiative forward within a newly developed ITMIG patient working group, joining forces internationally for future patient engagement and better outcomes for those affected by thymic cancers.

Cancer52 – Parliamentary Event

ThymicUK is an active member of Cancer52, the umbrella charity for rare and less common cancers in the UK. In November, all three of our trustees, Karen, Marrika and Heidrun helped raise awareness at a Parliamentary Reception, organised by Cancer52's Honorary President and sponsored by House of Lords' Member Baroness Morgan of Drefelin. The event showcased case studies from four different member charities who had successfully collaborated with the NHS on projects benefitting people living with rare and less common cancers.

BTOG Special Interest Group for Thymic Malignancies & Progress with Thymic Cancer Database

Throughout 2025, we have continued our important work as members of the BTOG Special Interest Group for Thymic Malignancies, with ThymicUK chair and founder Karen Ruddock representing the patients' voice, and Marrika Colvin representing Clinical Nurse Specialists.

Progress has been made in the setting up of a nationwide Thymic Epithelial Tumours (TET's) Registry, which will allow researchers and health care professionals to gain crucial insights which can lead to better care and outcomes for patients. As a collaborative platform between hospitals and clinicians across the UK, the registry will promote the need for the development of national guidance and lead to more effective and standardised treatments and management protocols. The Registry is now enrolling new patients into a prospective study at 5 hospital sites (Guys and St Thomas's Foundation Trust, Cambridge & Royal Papworth, Leeds Teaching hospital, The Christie & Manchester University Foundation Trust and University Hospital Sussex) with hopefully more set to join as well as retrospective data from current patients. We will keep you updated on this important resource.

Cranfield Trust support

We are delighted that we have successfully secured pro bono support from the Cranfield Trust in May, helping us develop the charity and what it can provide in a way that is both ambitious and sustainable. You may know that we (Karen, Marrika and Heidrun) volunteer all our time, that we do the charity work from home, and that any money raised or donated goes directly to the charity to help us achieve our goals. We are currently focused on building our strategy for 2026 and beyond and are

grateful to volunteers in this process from within and outside the group. In the future, we will reach out to the group for volunteers to help us with small one-off or some regular tasks, so we can achieve more together.

Awareness Wristbands now available

Next to our popular ThymicUK badges and ribbons, you can now help raise awareness for thymic cancers by wearing one of our new 'I'm supporting ThymicUK' wristbands. Suggested by members previously we are very pleased to share that you can now order your wristbands via our website (https://www.thymicuk.org/shop) for just £2 (covering item and postage) or you can chose £5 or £10 (adding a small donation to the order). We want to make sure that everyone can show their support and help raise awareness.

Group's Growth and Reach

With more than 80 new joiners to our Facebook support group alone, our community is getting ever stronger. More health care professionals (nurses in particular) seem to be aware of and signpost to ThymicUK, and more patients (newly diagnosed or living with thymic cancers since many years) seem to find us more easily.

It is amazing to see the often very practical mutual support through the sharing of experiences, and how everyone is there for one-another. A larger group comes with new challenges and opportunities, and we want to do better in 2026 keeping you informed and involving you more in our ongoing work and the dreams we have. Together we can achieve much more.

We also want to take a moment to remember those we have lost. Our thoughts are with their loved ones.

Fundraising and Donations

As an entirely volunteer-run organisation, all funds go directly to our charity aims. They enable us to do the work we do, from providing the website to running webinars and raising the patients' voice at events. We saw fewer donations and fundraisers in 2025 but are very grateful for every single one of them. Thank you!

Overall, 2025 has been a year of important collaborations, - continued and new - all focused on making sure the patients' voice is heard and actions are taken. Our close work with and as part of key organisations such as BTOG, ITMIG, and Cancer52 enables us to advocate for, shape, and support key initiatives to improve the quality of care and outcomes of those affected by thymic cancers in the UK. The more we as ThymicUK are present and seen as a trusted partner, the stronger and more impactful our collaborations become. This in turn leads to more signposting to us and to more patients, health care professionals and organisations hearing about ThymicUK and the work we do. As our community of patients and carers grows, we and our voice strengthens. We very much look forward to 2026 and to achieving even more together.

Karen, Marrika & Heidrun