

# thymicUK 2024

## A YEAR OF SIGNIFICANT CONTRIBUTIONS AND COLLABORATIONS

We are pleased to present a comprehensive overview of our charity's activities in 2024, highlighting key initiatives, collaborations, and events that have raised awareness and improved patient care.

### British Thoracic Oncology Group [BTOG] Conference 2024

Our participation at the BTOG 2024 Conference in April in Belfast was an important opportunity to build new relationships, foster existing ones, and continue collaboration on ongoing initiatives. The 2024 conference counted over 1000 attendees including 70% healthcare professionals and 3% patient advocates. Over three packed conference days, we raised awareness of thymic cancers from our ThymicUK charity stand and kept pushing the agenda to improve patient outcomes. ThymicUK trustees have attended BTOG annual conferences since 2019, often wearing multiple heads: as patient advocates, as exhibitors with a charity stand, and even as research authors (2023), and as co-chair of a session dedicated to thymic malignancies (2024, see below).

### Dedicated Thymic Malignancies Session at BTOG 2024

The 2024 BTOG Annual Conference featured a session entirely dedicated to thymic malignancies. It was chaired by Dr David Gilligan and by our very own trustee, Marrika Colvin, a Clinical Nurse

Specialist at Guys and St Thomas' hospital. The session included five outstanding presentations and was well attended, reflecting the growing interest and importance of this field. This session was crucial in raising awareness and we believe will impact patient outcomes.

### Launch of Anterior Mediastinal (suspected Thymic) Lesion Diagnostic Pathway

BTOG has only two Special Interest Groups (SIGs), one of which is the SIG for Thymic Malignancies, chaired by Dr David Gilligan (see above).

ThymicUK has been a driving force in the creation of this SIG, and ThymicUK founder and chair Karen Ruddock has been a member from the start, representing the patient voice. Our trustee and Clinical Nurse Specialist, Marrika Colvin is also a SIG member.



Thymic Malignancies

Friday, 19 April at 14:45 - 16:45  
Main Auditorium

Chairs: David Gilligan (ENG) and Marrika Colvin (ENG)

In 2024, the BTOG Special Interest Group for Thymic Malignancies proudly launched the Anterior Mediastinal Pathway, a new diagnostic algorithm designed for anterior mediastinal lesions. The group has developed this pathway through

multidisciplinary discussion and identification of best practice under the coordination of Dr Stephen Robinson and Professor Matthew Evison. This initiative aims to standardise the management of these lesions across the UK, fostering improvements in patient care. The pathway represents a significant step toward uniformity in diagnostic and treatment approaches, benefiting patients nationwide.

## Working towards a comprehensive Thymic Cancer Database; a Thymic Epithelial Tumours (TETs) Registry

ThymicUK has long been advocating for the need of a comprehensive database that would allow healthcare professionals to bring together information on the rare cases of thymic malignancies, to advance learning and ultimately lead to more effective and safer treatment regimes.

ThymicUK actively supports the setting up of a nationwide TET registry which is spearheaded by BTOG SIG members, Dr Eleni Josephides and Dr Eleni Karpanagiotou, based at London's Guys and St. Thomas' Hospital. The proposed comprehensive database will allow the observation and identification of responses to treatment regimens and recurrence trends between patients with similar TET profiles. It aims to serve as a collaborative platform between hospitals and clinicians around the UK and to promote the need for the development of more effective treatments and management protocols for patients with TETs. In turn this will empower patients and their families by contributing to TET research that can lead to earlier diagnoses, better-informed treatment decisions and evidence-based surveillance plans. The application is currently under review, and some of our ThymicUK members have helped shape it by providing feedback on a draft patient information sheet in September.

## Research on Clinical Trials Search by Clinical Net

Clinical Net is a relatively new, free website, patients can use to search for potentially suitable

trials. From the start, Clinical Net has actively sought patient feedback, including our own, and has continuously improved the website functionality and user friendliness. With now over 75,000 searchable open trials globally (source: <https://www.clinicalnet.com/>) Clinical Net are looking for patients who might be willing to participate in a study that assesses the effectiveness of methods used to match patients to trials. We have embedded a tab entitled 'Find Clinical Trials' at the top of our website (<https://www.thymicuk.org/>); if you access Clinical Net through this tab between now and March 2025, you will be given more information on the research study and can choose to take part or continue your trial search as normal.

## Third International Thymic Malignancies Awareness Month

In May 2024 we held our 3<sup>rd</sup> International Thymic Malignancies Awareness Month in collaboration with the International Thymic Malignancy Interest Group (ITMIG). It included a series of events and webinars to help increase the knowledge of these rare cancers among patients and their families, as well as among doctors of various specialties who do not deal with mediastinal diseases on a daily basis. Recordings of the ITMIG webinars can be accessed via <https://itmig.org/tmam/>. For a recording of ThymicUK's Awareness Month Patient Webinar, see below.

## Patient Webinars

ThymicUK hosted two patient webinars in 2024 and a Social Xmas Meeting, providing a supportive platform for patients to share their experiences, receive updates on the latest research, and gain valuable insights from medical professionals. These meetings are integral to our mission of fostering a strong, informed patient community.

During the Awareness Month in May we held a Patient Webinar, with presentations by Dr David Gilligan and Dr Eleni Josephides (recording at [https://youtu.be/\\_no9vRJOKEI?feature=shared](https://youtu.be/_no9vRJOKEI?feature=shared)). It was well attended and great to see positive feedback to the webinar in our support group where it was described as informative, useful and clear,

and even recommended as a must see for new patients. Our September Patient Webinar (recording at <https://www.youtube.com/watch?v=071ZIFIZaAY>) included presentations on Energy Conservation, Pain Management, and Physiotherapy post Thymectomy Surgery, as well as an introduction to Maggie's UK on the challenges of rare cancers.

## Cancer52 Health Inequalities Report

We are a member of Cancer52, the umbrella charity for rare and less common cancers in the UK. In July, 44 of our members took part in a Patient Survey to identify Health Inequalities which has led to a very interesting report which can be accessed on the Cancer52 news page.

## Group's Growth and Increase of Awareness

2024 has been a year of significant growth for our Support Group and Mailing List. Due to our work, advocating for patients, attending conferences, producing information leaflets and awareness badges, running a dedicated website, collaborating with relevant medical bodies, posting on social media etc., patients and carers seem to find us more easily. More and more healthcare professionals are aware of our charity and support group and are able to signpost to us. We have seen an increase in awareness of thymic cancers and our charity's aims, thanks to the dedication of our members, our ongoing efforts, expanding network and the enhanced visibility we all work towards.

We are continually blown away by the care and support that our members show for each other. Members take time to share their experiences which in turn helps guide and empower others in their choices. Almost every day there are posts



In conclusion, 2024 has been a year of remarkable achievements and collaborations. We remain committed to our mission of raising awareness, for advocating and providing support to those affected by thymic cancers, of supporting research and the development of safer and more effective treatments to improve patient outcomes. We look forward to continuing this journey with the support of our dedicated members and partners.

*Karen Ruddock* (Chair ThymicUK)

from members asking questions, sharing experiences, and giving emotional support. This is something we are very proud of.



## ThymicUK Regional Social Representatives

In the summer, we started a new initiative: Regional Social Reps. We currently have 11 amazing support group members who act as Social Reps in their region, covering many areas throughout the UK and Ireland. We believe that regional social gatherings or just getting to know support group members who live closer by can be important for everyone's wellbeing. There is value in meeting another person who understands what you are going through.

## Fundraising and Donations

Our members have continued to support ThymicUK through fundraising, with donations and through buying awareness badges/ribbons. As an entirely volunteer-run charity, all funds raised go directly to our aims, and we are very grateful for all your support.