



Thymic Malignancy Interest Group Annual Meeting

October 2-4, 2025 Milan, Italy

The value of patient support groups: TUTOR's story

L. Abate-Daga,
President TUTOR APS ETS
E-PAG Euracan ERN

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associazione tumori toracici rari

 European
Patient
Advocacy
Group

Tumori Toracici Rari 11/2017

- Rare Thoracic Tumors Italian patients'/families/volunteers org.
- Since 11/ 2017: TET
- Since 4/2021: Pleural Mesothelioma



facilitator

E-PAG Since 10/2021

- European Patient Advocacy Group at EURACAN ERN European Reference Network (euracan.eu)
- **giving voice" to the needs of patients"** in ERNs' activities.
- Actively involved in the ERNs, working in partnership with clinicians and researchers.

*Support for those having to cope with **Rare ThOracic TUMor (TU.TO.R.)** giving them a concrete help to better cope with thymic tumors and mesothelioma*

ADVOCACY



- Ad-voco «*to add a voice*»
- «The voice of the unheard»
- Activating series of initiatives to start a **process of change**

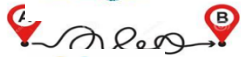
CHALLENGES TET's PATIENTS/FAMILIES FACE...



Overwhelmed and Alone



Few information available



A long and challenging journey to diagnosis



Lack/shortage of doctors with relevant expertise (auto-refer)



Disrupted or no access to appropriate care and medicine



Few available treatment options/ Orphan cancer

**Thymic Malignancy
Interest Group**

Rare Cancer Agenda 2030

Ten Recommendations from the JARC:

1. Rare cancers are the rare diseases of oncology
2. Rare cancers should be monitored
3. Health systems should exploit networking
4. Medical education should exploit and serve healthcare networking
5. Research should be fostered by networking and should take into account an expected higher degree of uncertainty
6. Patient-physician shared clinical decision-making should be especially valued
7. Appropriate state-of-the-art instruments should be developed in rare cancer
8. Regulation on rare cancers should tolerate a higher degree of uncertainty
9. Policy strategies on rare cancers and sustainability of interventions should be based on networking
10. Rare cancer patients should be engaged



RARE CANCER AGENDA 2030

Ten Recommendations
from the EU Joint Action on Rare Cancers



Patient-physician shared clinical decision-making should be especially valued...

...being crucial to the appropriate approach to the high degree of uncertainty posed by rare cancers

Rare cancer patients should be engaged...

...in all crucial areas, such as disease awareness and education, healthcare organization, state-of the-art instruments, regulatory mechanisms, clinical and translational research

Consequently, in order to achieve economies and synergies, it is important that patient organizations work **as far as possible in partnership, not just with one another, but also with other stakeholders**, including **companies, regulators, healthcare professionals, politicians and academics**.



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**Thymic Malignancy
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RARE not ALONE

3°thursday

"A Time for Patients to meet and share"



RARE and Uncommon

Access to information, resources on
Thymoma and Thymic Carcinoma:

Center of expertise

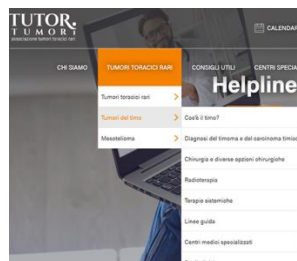
clinical trial

services/activities

www.tutortumori.org

Linkedin @associazionetutor

Fb @associazionetutor



EMPOWERMENT/ENGAGEMENT



established
by
ITMIG



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EURACAN

Interactive ONLINE multidisciplinary sessions to enhance learning and engagement.

Promote patient **centricity and participation** in the care pathway

**Webinar recordings can be accessed on
TUTOR's/ITMIG website**



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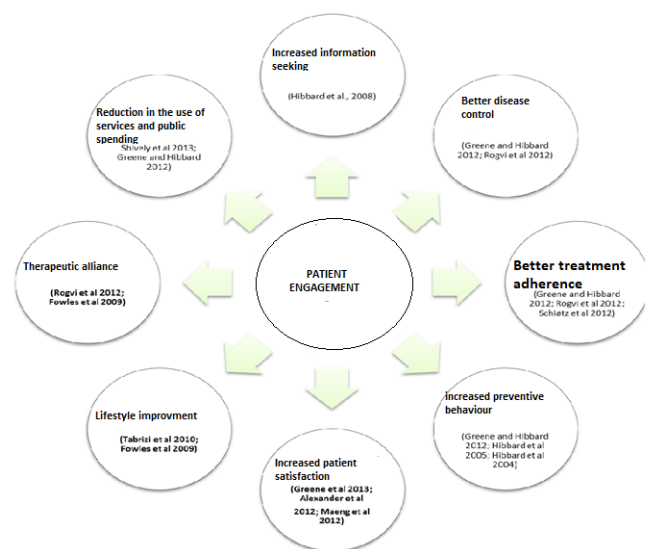
Engagement & Collaboration



ENGAGEMENT PARTICIPATION

Patients actively participating in their care discussions.

CLINICAL AND SCIENTIFIC EVIDENCE CONFIRM THE VALUE OF PATIENT ENGAGEMENT FOR SHARE DECISION MAKING



COLLABORATION PARTNERSHIP RARE CANCER PATIENTS SHOULD BE ENGAGED



Strengthen and expand collaboration and dialogue with the **clinical and scientific** community involved in TET and related conditions.

- 1) Governance (SC+WG/scientific board)
- 2) National Congress together TYME-TUTOR (bringing patients point of view/needs)



EURACAN



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Board member
E-PAG Coordination Team



Member of:

- Communication Committee with other patient organizations
- Membership Committee / Paolo Mendogni



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Research & Future



RESEARCH COLLABORATION

NETWORK ENHANCE RESEARCH FOR TREATMENT OPTIONS

- The World Health Assembly WHA75.8 resolution on strengthening clinical trials to provide high-quality evidence on health interventions recognises the central role of stakeholder engagement
- Engaging patients, the public, and community stakeholders throughout the clinical trial lifecycle—from design to dissemination—improves trial relevance, feasibility, and acceptance within the community

Value of Partnership: Advances in Chordoma Research

	2011	2017	Observations
Research community	Small, disconnected	>100 active researchers, robust collaboration	International Chordoma Research Workshops, networking events
Patient community	None	>1,000 patients	Patient-led group, website, online advertising and search engine optimization, educational materials, Chordoma Community Guidelines
Tumor tissue	Scarce, no centralized source	Established repository with tissue from >200 cases	Tumor donation program allows patients to donate tumor from any US hospital, CP: Bankers store and distribute tumor samples
Genome characterization	None	35 cases sequenced	Chordoma Genome Project, in partnership with academic labs
Cell lines	1	17	Cell line prices, cell line validation pipeline, genome characterization publicly accessible, cell line repository
Patient-derived xenografts (PDX)	None	5	Tumor donation program hospital with rapid implementation at sites, PDX prices, PDX validation pipeline, publicly accessible PDX repository
Small molecule screening	None	>15,000 compounds screened, including all FDA-approved drugs	Collaboration with NIH Chemical Genomics Center, grants to academic investigators, collaborations with industry
Functional genomic screening	None	Genome-wide CRISPR/Cas9 screens, targeted shRNA screen	Grants to academic investigators
In vivo evaluation	None	>10 drugs evaluated	CP drug screening, positive results in vivo evaluated as a service to academic and industry collaborations
Clinical trials	1 completed clinical trial	Pipeline of 7 new clinical trials	Clinical trial program supports trials with funding, trial design, patient education, and outreach

Source: National Chordoma Foundation (NCF). Sources: general correspondence and www.ncfchordoma.org

Sharifia T. Cell Chem Biol. 2017;24:1075-1091.

THE LANCET Global Health

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Better engagement, better evidence: working in partnership with patients, the public, and communities in clinical trials with involvement and good participatory practice

REVIEW

Elements of successful patient involvement in clinical cancer trials: a review of the literature

I. Shakhnenko¹, O. Husson^{2,3}, D. Chuter^{4,5} & W. van der Graaf^{2,6,*}

¹European Organisation for Research and Treatment of Cancer (EORTC Headquarters), Brussels, Belgium; ²Department of Medical Oncology, Netherlands Cancer Institute, Antoni van Leeuwenhoek, Amsterdam; ³Department of Surgical Oncology, Erasmus MC Cancer Institute, Erasmus University Medical Centre, Rotterdam, The Netherlands; ⁴EORTC Patient Panel, Brussels, Belgium; ⁵Digestive Cancers Europe (DICE), UK; ⁶Department of Medical Oncology, Erasmus Medical Centre Cancer Institute, Erasmus University Medical Centre, Rotterdam, The Netherlands

Research Network and Patients involvement, to solve

Limited resources and data
Scarce tumor samples
Small patient populations.
Lack of support



Give a therapeutic options for patients all around the world

**IF YOU WANT
TO GO FAST,
GO ALONE.**

**IF YOU WANT
TO GO FAR,
GO TOGETHER.**

THANK YOU

Laura Abate-Daga

Laura.abatedaga@tutortumori.org

+39 3351203920



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