The value of patient support groups: TUTOR's story

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associazione tumori toracici rari

European Patient Advocacy Group

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Tumori Toracici Rari 11/2017

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

TYME facilitator

E-PAG Since 10/2021

- **E**uropean **P**atient **A**dvocacy **G**roup 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

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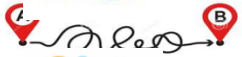
ADVOCACY

- 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

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

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.**

Patient Support & Empowerment

COMMUNITY CONNECTION

RARE not ALONE

ONLINE monthly meeting in english

3°thursday

"A Time for Patients to meet and share"

INFORMATION KNOWLEDGE

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

May Thymic Malignancy Awareness Month established by ITMIG

European Patient Advocacy Group 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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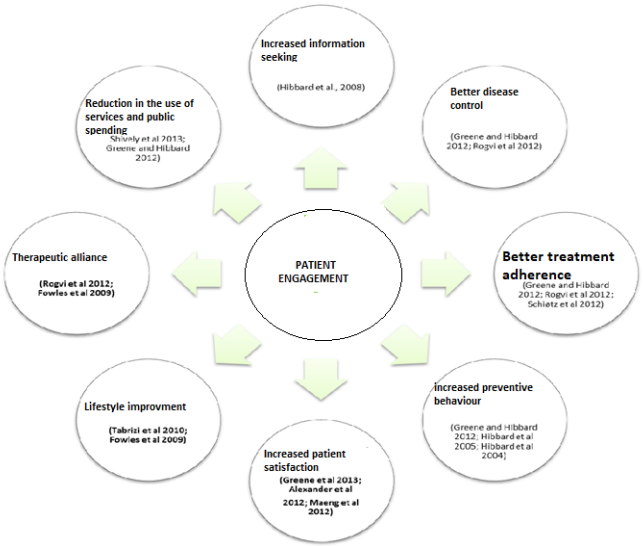
Engagement & Collaboration

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

European Patient Advocacy Group

Board member
E-PAG Coordination Team

ITMIG International Thymic Malignancy Interest Group

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 provid 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


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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. Shakhnenko[1], O. Husson[2,3], D. Chuter[4,5] & W. van der Graaf[2,6*]

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

Value of Partnership: Advances in Chordoma Research

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

Finding the missing pieces: Empowering Collaboration

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

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IF YOU WANT
TO GO FAST,
GO ALONE.

IF YOU WANT
TO GO FAR,
GO TOGETHER.

THANK YOU

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