

Rare cancers: the role of patient advocates in raising awareness



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International
Brain Tumour
Alliance (IBTA)
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Training Course
for Rare Cancer
Patient Advocates

Disclosure of Interests (2005 to date)

International Brain Tumour Alliance (IBTA)

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Patient Advisory Boards: Novartis, Bristol-Myers Squibb, AbbVie, GSK, Lilly, Novocure

Committees/Projects: EURACAN, All.Can, ECCO Patient Advisory Committee, Rare Cancers Europe, GLIOTRAIN, EORTC SISAQOL project, SNO Guidelines Committee, WECAN, INSERT, NCRI Brain Tumour Subgroup on Palliative and Supportive Care, EANO Palliative and Supportive Care Task Force, NCI-CONNECT

For full details of the IBTA's sponsorship policy, and comprehensive details of our funding organisations, please see our website at www.theibta.org

Rarity...



A rare 76 carat diamond valued at US \$15 million



Rare kangaroo stamps (Australia)



Rare aurora borealis butterfly (South America)



A rare golden snub-nosed monkey (China)



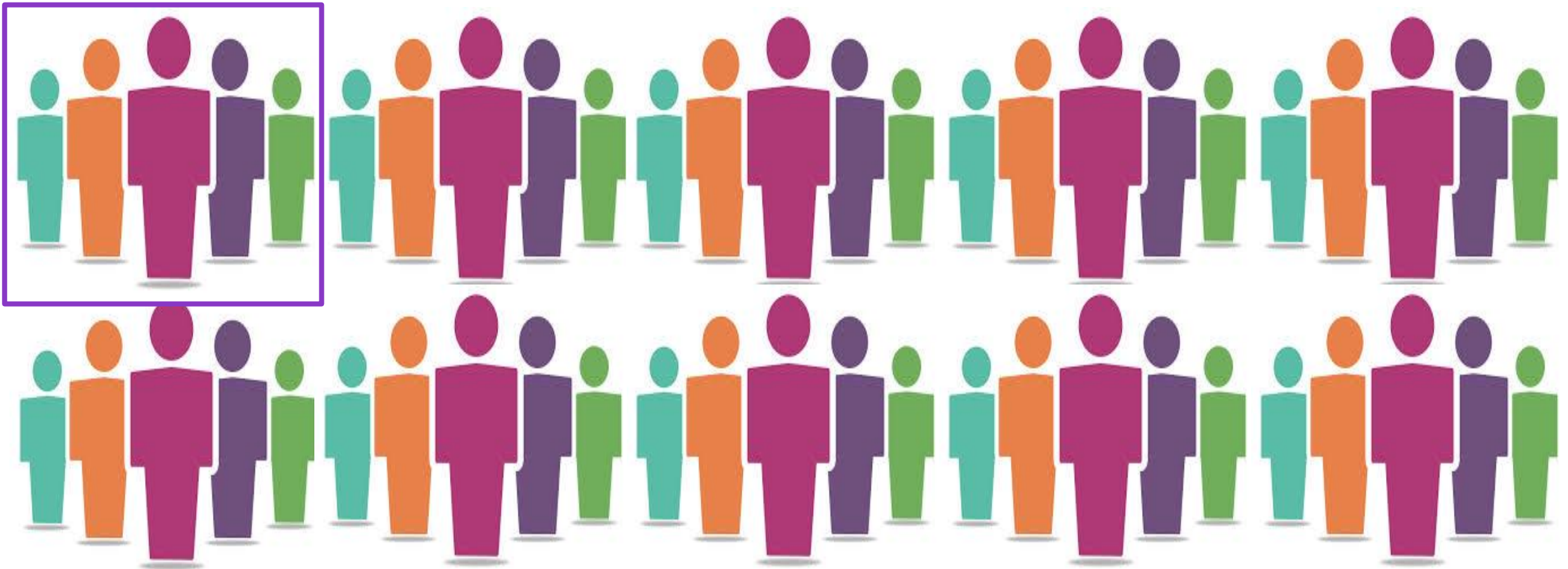
Painting by M'Liz Keefe (USA), sister of a young glioblastoma brain tumour patient

5.1 million Europeans are affected by a rare cancer*



And if every person with a rare cancer in Europe stood next to each other holding hands, then 5.1 million people would stretch 4,000 kilometres which is the entire breadth of Australia, from Perth to Sydney AND beyond.

Rare cancers = an incidence of less than 6 people in 100,000 per year *



* Rare Cancers Europe: <https://www.rarecancerseurope.org/>

There are nearly 200 different types of rare cancers

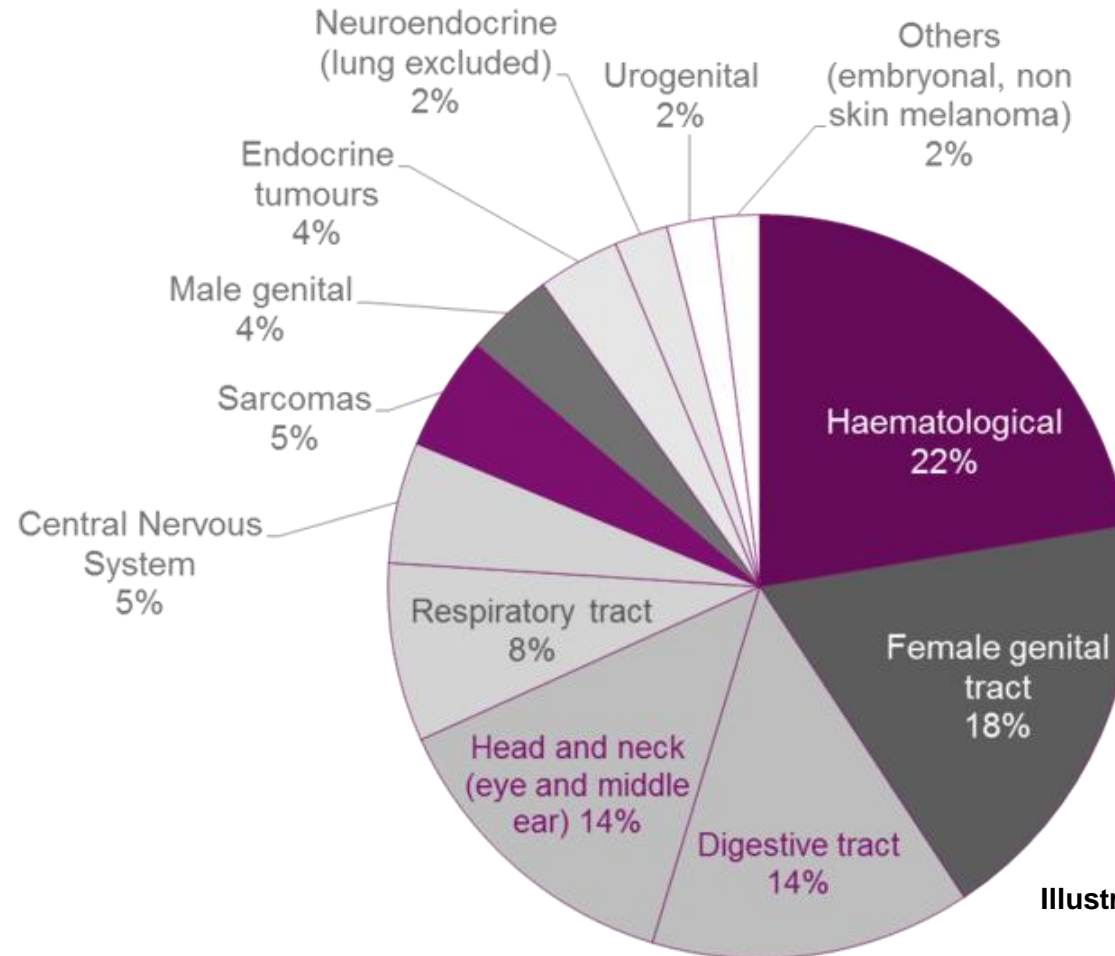


Illustration courtesy of Rare Cancers Europe

Distribution of “families” of rare cancers



Together, rare cancers represent about 24% of all cancer cases diagnosed in the European Union each year, including rare adult solid tumours (13%) and rare haematological cancers (8%) as well as all childhood cancers (1%).

Some of the challenges of rare cancers...

Prevention and screening
mostly irrelevant

Late or incorrect diagnosis

Lack of information and
patient groups

Widespread, small
populations of patients

Shortage of local medical
expertise

Incomplete registries and
tissue banks

Methodological barriers
(in traditionally-designed
clinical trials)

Not enough clinical trials
for rare cancers

Regulatory barriers

Reimbursement
challenges for treatments

Inequitable access to
therapies and care

Stigma

**Rare cancer (five
year relative)
survival is worse at
48.5% than common
cancer at 63.4%. ***

For rare cancers, there are four relevant ERNs:

ERN PAEDCAN



EURACAN
European network for
Rare adult solid Cancer


The background on ePAGs

EURORDIS established ePAGs and acts as a coordinator of them across the ERNs. Representatives of ePAGS are selected based on stringent criteria:

- cancer patient advocacy track record
- knowledge of European healthcare policies and institutions
- working experience in EU healthcare projects and with clinicians, researchers, regulators and others

The role of ePAGs

- ensure that care is **patient-centred** and there is respect for patients' rights and choice
- ensure **transparency** in quality of care, safety standards, clinical outcomes and treatment options
- ensure that **ethical issues** for patients are addressed
- contribute to the development of **patient information, policy documents, good practice, care pathways** and **guidelines**
- advise on **planning, monitoring** and **evaluation** of ERN initiatives
- Help disseminate information about ERNS to patient and medical communities

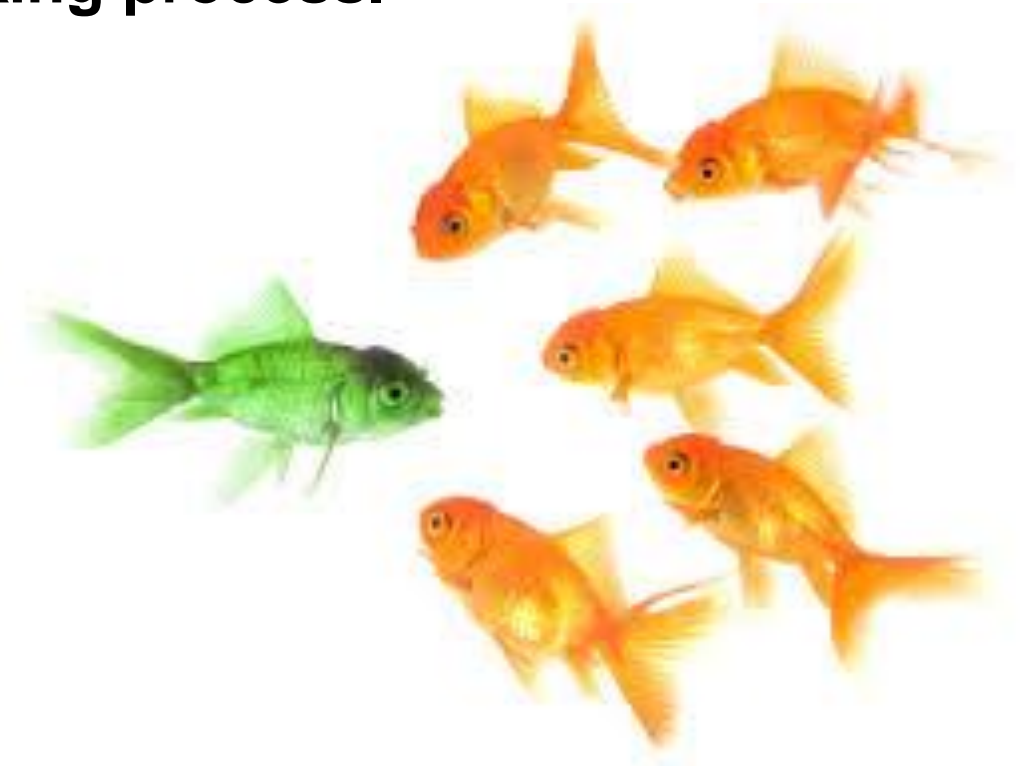


Patient advocacy and awareness-raising addresses unmet needs and gaps in healthcare provision so that optimal treatment, care and support are delivered to rare cancer patients, their caregivers and families.

Why are rare cancer patient perspectives important?

If your life or your quality of life depends on the results of a decision, then you need to be at the heart of that decision-making process.

- Patients are no longer passive recipients of medical care
- Patient engagement creates a win-win situation for people, healthcare services and policy
- Patients may throw an important, different light on conventional wisdom



The patient advocacy perspective brings:

- Value
- Knowledge
- Experience
- Change



Patients' rights activism in the United States in the 1970s led to widespread social action and healthcare system reform.



From the collection of the US National Library of Medicine, NIH

The HIV/AIDS movement in the 1980s and 1990s brought massive change in the medical research paradigm.



A 1985 protest in New York City, the hub of the AIDS epidemic and the corresponding art movement. Source: <https://mashable.com/2016/10/26/aids-epidemic-study/>



What does rare cancer patient advocacy look like?

Patient advocacy upholds the notion that every patient living with a rare cancer should be valued, respected, listened to and as involved with their own care as they wish to be.

What does cancer patient advocacy look like?



Liaise between patients and their medical professionals

Defend patients' rights

Lobby government for policy change

Raise funds for research and support

Build knowledge and capacity in patient communities

Address the challenges of patient-centred care

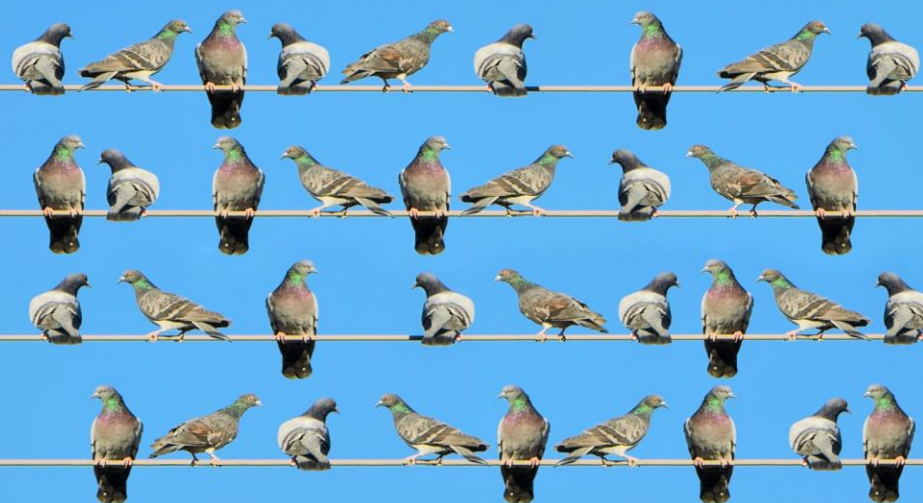
Provide educational materials

Support and empower patients, their families and caregivers

Raise awareness

Help reduce anxiety, uncertainty and fear

Sustain hope



Training for cancer patient advocates



**RCE-ESO-ESMO Training
Course for Rare Cancer
Patient Advocates**



WECAN
SmartStart
in Cancer Patient Advocacy



Evidence-Based Advocacy Course



WECAN
MASTERCLASS
in Cancer Patient Advocacy



WECAN Science



What can you do for your rare cancer community?

| | |
|------------------------|---|
| Raise Awareness | Raise awareness of rare cancers on a national policy level in your country to ensure that European Reference Networks such as EURACAN are built on the strong foundations of national rare disease and rare cancer plans. |
| Support | Support efforts for new national centres of expertise in your country for rare cancers. |
| Know | Get to know the healthcare professionals in your country who are dealing with the rare cancer for which you want to raise awareness. |
| Respect | Respect the challenges that healthcare professionals have every single day. |
| Build bridges | Help to break down silos and instead build bridges between the stakeholders in your rare cancer field. Identify unmet needs and gaps in healthcare provision. |
| Learn | Learn about national healthcare policies for rare diseases in your country. |
| Don't give up | Don't give up – you WILL make a difference. |

Rare cancers...we're getting there



Thank
you!



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The International Brain Tumour Alliance

R
CANCERS
EUROPE
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