EURACAN:
what it means to adult patients with rare solid tumours

ESMO-ESO-RCE Training Course for Rare Cancer Patient Advocates – 2 December 2017 - Milan, Italy
Presented by Kathy Oliver, Chair, International Brain Tumour Alliance (IBTA)
The International Brain Tumour Alliance (IBTA)
In 2017 the IBTA has, to date, received funding support from: Bristol-Myers Squibb, AbbVie, MagForce, Photonamic, Novocure, Novartis, Northwest Biotherapeutics, Pfizer and VBL

The IBTA (to date)
Patient Advisory Boards – Novartis, Bristol-Myers Squibb, AbbVie

Kathy Oliver Consulting (to date)
Patient Advisory Board – GSK, Lilly

For full details of our sponsorship policy, and comprehensive details of our funding organisations in the years 2005 to 2017, please see our website at www.theibta.org
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Misdiagnosis
Fear

The Scream by Edvard Munch, Flickr
Isolation  Uncertainty  Struggle

*Sorrowing old man (at Eternity’s Gate)* by Vincent Van Gogh, Flickr
Fragmentation
Disparities
Stigma

I am not a label.
I am an individual person with hopes and dreams.
Just like you.
Alone
EURACAN – the European Reference Network for rare adult solid tumours and its ten domains and subdomains

EURACAN kicked off Officially on 21st and 22nd April 2017 in Lyon, France.
What are European Reference Networks (ERNs)?

ERNS are networks of networks involving specialist healthcare providers across Europe. ERNs exist in order to:

(1) enable the sharing of expertise within networks and

(2) to improve access to care for patients across the European Union, especially for complex or rare diseases that require highly specialised healthcare and a concentration of knowledge and resources.

(3) securely facilitate patients’ data travelling across borders

ERNS have been established under the 2011 EU Directive on patients’ rights in cross-border healthcare. This Directive makes it easier for patients to access information on healthcare and thus increase their treatment options.
More than 4.3 million people in the European Union are living with a rare cancer. *

Despite the rarity of each of the 198 rare cancers, they represent in total about 22% of all cancer cases, including all cancers in children, diagnosed in the EU each year. *

* Rare Cancers Europe/RareCare
FOUR ERNS RELEVANT FOR RARE CANCERS

1. Rare adult solid cancers (EURACAN)

1. Pediatric cancers (PaedCan-ERN)

1. Haematological cancers and other rare haematological diseases (EuroBloodNet)

2. Rare inherited syndromes which may give rise to various cancers, for example, Li-Fraumeni Syndrome which can give rise to brain tumours (Genturis)
Rare adult solid cancers are grouped in 10 domains corresponding to the RARECARE classification and the ICD10.

These domains are also based on pre-existing successful collaborations, in particular for clinical research and expert networks active in the last 10-20 years.
# THE TEN DOMAIN LEADERS

<table>
<thead>
<tr>
<th>Domain</th>
<th>Leader Name</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>G1 Sarcoma</td>
<td>CASALI Paolo</td>
<td>Istituto Nazionale dei Tumori, Milan, Italy</td>
</tr>
<tr>
<td>G2 Rare GYN</td>
<td>SECKL Michael</td>
<td>Imperial College London, United Kingdom</td>
</tr>
<tr>
<td>G3 Rare GU</td>
<td>GIETEMA Jourik</td>
<td>University Medical Center Groningen, The Netherlands</td>
</tr>
<tr>
<td>G4 NET</td>
<td>CAPLIN Martyn</td>
<td>Royal Free London NHS Trust, United Kingdom</td>
</tr>
<tr>
<td>G5 GI</td>
<td>WYRWICZ Lucjan</td>
<td>M Sklodowska-Curie Memorial Cancer Center, Warsaw, Poland</td>
</tr>
<tr>
<td>G6- Endocrine</td>
<td>BAUDIN Eric</td>
<td>Gustave Roussy- Villejuif, France</td>
</tr>
<tr>
<td>G7 Rare Head and Neck</td>
<td>LICITRA Lisa</td>
<td>Istituto Nazionale dei Tumori, Milan, Italy</td>
</tr>
<tr>
<td>G8 Rare Thoracic</td>
<td>GIRARD Nicolas</td>
<td>Hospices Civils de Lyon, France</td>
</tr>
<tr>
<td>G9 Rare Skin/Eye melanoma</td>
<td>SCHADENDORF Dirk</td>
<td>University Hospital Essen, Germany</td>
</tr>
<tr>
<td>G10 Brain tumours</td>
<td>VAN DEN BENT Martin J</td>
<td>Eramus MC, Rotterdam, the Netherlands</td>
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</tbody>
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DISTRIBUTION OF EURACAN MEMBERS BY COUNTRY

Countries (organizations) participants to EURACAN

BELGIUM (Antwerp, Brussels, Leuven, Liège)
CZECH REPUBLIC (Brno, Prague)
DENMARK (Aarhus)
GERMANY (Berlin, Essen, Mannheim, Hamburg—Eppendorf, Marburg, Würzburg)
FINLAND (Turku)
FRANCE (Lyon, Paris, Villejuif)
HUNGARY (Budapest)
IRELAND (Dublin)
ITALY (Aviano, Bologna, Candiolo, Firenze, Genoa, Meldola, Milan, Naples, Roma, Siena, Torino, Treviso)
LITHUANIA (Kaunas)
NETHERLANDS (Amsterdam, Leiden, Maastricht, Nijmegen, Rotterdam, Groningen)
NORWAY (Oslo)
POLAND (Warsaw)
PORTUGAL (Coimbra, Lisboa, Porto)
SWEDEN (Karolinska, Uppsala)
SLOVENIA (Ljubljana)
UNITED KINGDOM (Conventry, London, Oxford, Sheffield)
EURACAN’S OBJECTIVES

- Increase access to pathological diagnosis and associated treatments across all EU MS
- Develop medical training programmes to increase and harmonise the quality of care
- Involve patient advocacy groups and assist them in the wide dissemination of educational tools
- Implement “roadmaps” for referral and self-referral of patient to expert centers
- Increase enrolment in clinical trials
- Develop and continuously review clinical practice guidelines (CPGs)
- Initiate and promote novel translational research programs (and associated tools e.g. set of multinational databases and tumour banks)
- Interact with key national and international individuals/networks involved in cancer care and research and beyond, with other rare diseases stakeholders.
What are ePAGs and what do they do for EURACAN?

ePAGs are elected patient representatives from patient advocacy organisations who make sure that the patient voice is heard throughout the ERN development process and beyond. The ePAG concept has been developed by EURORDIS, Rare Diseases Europe.

ePAGs also serve on EURACAN’s steering committee and on its transversal task forces.
## ePAG REPRESENTATIVES’ ROLES IN ERNs

<table>
<thead>
<tr>
<th>Key roles (Governance)</th>
<th>Key objectives (Care)</th>
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<tbody>
<tr>
<td>• Present and represent the patient voice, providing patient experience</td>
<td>• Ensure transparency in quality of care, safety standards, clinical outcomes and treatment options.</td>
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<tr>
<td>• Communicate and connect with our community</td>
<td>• Promote a patient-centric approach in both delivery of clinical care, service improvement and strategic development and decision-making.</td>
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<tr>
<th>Key roles (Monitoring &amp; Evaluation)</th>
<th>Key objectives (research)</th>
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<tr>
<td>• Review effectiveness of network empowering patients, evaluate how network acts on feedback received</td>
<td>• Contribute to the definition of research priority areas based on what is important to patients and their families.</td>
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<td></td>
<td>• Ensure that patients are embedded in the research activities performed within the ERN, including involvement in the assessment of clinical trials and in ethics committees.</td>
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The Scream by Edvard Munch, Flickr
"Over the next five years, as the ERNs reach full capacity, thousands of EU patients suffering from a rare or complex condition can expect to benefit." (EU leaflet on ERNs)

eck.europa.eu/health/ern
Spread the word!

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Thank you for listening and...

a special thank-you to the EURACAN team in Lyon, France and the ERNs team at EURORDIS, Paris, France for the use of some of their slides in this presentation,