European Action Against Rare Cancers

The rare cancer perspective

Paolo G. Casali
paolo.casali@istitutotumori.mi.it
European Action Against Rare Cancers

RARE CANCERS: MORE COMMON THAN YOU THINK!

☐ Sign the call to ACTION AGAINST RARE CANCERS

www.rarecancers.eu
Rare Tumours in Europe
CHALLENGES AND SOLUTIONS
6 November 2008 - Brussels

11.15 –13:15 PARALLEL BREAKOUT SESSIONS INCLUDING WORKING LUNCH

**Workshop I**
**Rare tumours: Methodological and Regulatory Challenges**
Chair: Paolo Casali, ESMO - Co-Chair: Jan Lillemark, Swedish Medicines Agency
The orphan drugs approval process - Filippo De Braud, European Institute of Oncology
Current guidelines on efficacy assessment in the EU - Iordanis Gravanis, EMEA
Strategies for rare tumours in medical statistics - Paolo Bruzzi, National Institute for Cancer Research of Genoa
A parliamentary perspective - Jolanta Dickute, MEP
Discussion

**Workshop II**
**Rare tumours: Organisational Challenges**
Chair: Jean-Yves Blay, Conticanet - Co-Chair: Bertram Wiedenmann, Charité University Hospital Berlin
The challenge of rare tumours treatment in the EU - Peter Hohenberger, University of Heidelberg
The role of patient advocacy groups - Jan Geissler, European Cancer Patient Coalition
Developing networks in haematology - Rüdiger Heimann, Leukemia Network
Examples of overcoming the barriers - Thor Alvegard, Scandinavian Sarcoma Group & Markus Wartenberg, Sarcoma Patients EuroNet
Discussion

**Workshop III**
**Rare tumours: Patient Access Challenges**
Chair: Kathy Redmond, Cancer World - Co-Chair: Flaminia Macchia, Eurordis
Challenges and barriers: An overview - Yann Le Cam, Eurordis
Living with a rare tumour: a patient story - Ella Pybus, Meningioma UK
Discussion
Improving Rare Cancer Care in Europe
Recommendations on Stakeholder Actions and Public Policies

Whereas

A. Rare cancers\(^1\) belong to the group of rare diseases that are normally defined as diseases with a prevalence of less than 50 out of 100,000. Even when defined more conservatively by taking into account some peculiarities of natural history and prognosis (e.g., by selecting those cancers with an incidence rate around or lower than 5/100,000/year), rare cancers represent about 20% of all cases of malignant neoplasms, including all cancers affecting children and teenagers and many affecting young adults;

B. There are significant variations in incidence and mortality rates for different types of rare cancers. There are also significant survival differences for the same types of rare cancers between the EU member states;\(^2\)
Rare cancers – more common than most people think

Nearly half a million Europeans live with a rare cancer. Despite the rarity of each individual cancer type, rare cancers represent in total about 20% of all cancer cases, including all cancers in children.

Rare cancers are classified in the group of rare diseases which is defined in the European Union as diseases with a prevalence of fewer than 5 cases per a population of 10,000. As such, patients with rare cancers are faced with the same challenges as other patients living with a rare disease, such as lack of information, inefficient detection and practical obstacles to treatment and care, just because their condition is rare.

Against this background, the European Action Against Rare Cancers welcomes new policy initiatives, such as the European Commission’s Communication on Cancer. Within the framework of this and other already existing policy initiatives, including the European Commission’s Communication and the Council Recommendations on Rare Diseases, we urge European policy-makers to continue to outline targeted actions and policies that will help raise awareness and address the challenges faced by patients with rare cancers.

Reference: PRESS RELEASE

Please join us by signing the Call to Action Against Rare Cancers.

Sign the call for Action Against Rare Cancers
European Action Against Rare Cancers
new study designs
surrogate end points
methods to combine evidence
organization of studies

Brussels, 10 February 2012
Quality of care

European Action Against Rare Cancers
**Definition**

European Action Against Rare Cancers

prevalence $\leq 50 / 100,000$
The **RARECARE** definition

European Action Against Rare Cancers

incidence $\leq 6/100,000/year$
Rare cancers

European Action Against Rare Cancers

childhood
Rare cancers

European Action Against Rare Cancers

- hematological
- childhood
Rare cancers

European Action Against Rare Cancers

- Childhood
- Hematological
- Adult solid cancers
### Gynecological cancers

*(EUROCARE data)*

<table>
<thead>
<tr>
<th>Tissue Type</th>
<th>Inc. /100,000/y</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uterus, body, epithelial</td>
<td>10</td>
</tr>
<tr>
<td>Uterus, cervix, epithelial</td>
<td>6</td>
</tr>
<tr>
<td>Uterus, mesenchymal</td>
<td>1</td>
</tr>
<tr>
<td>Ovary</td>
<td>9</td>
</tr>
<tr>
<td>- non-epithelial</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Vulva, vagina</td>
<td>2</td>
</tr>
<tr>
<td>Trophoblastic</td>
<td>&lt;1</td>
</tr>
</tbody>
</table>
European Action Against Rare Cancers

Paolo G. Casali
paolo.casali@istitutotumori.mi.it