

RARE CANCERS 101

**Dedicated to the more than 4,000,000 people
in Europe affected by rare cancers**

**Presented by:
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www.theibta.org**



**9th ESMO Patient Seminar
Vienna, 30 September 2012**



Rare Cancers

Are there any therapies available to treat my rare cancer?

Will my treatment be in a centre of excellence?

How can we find other people affected by the same rare cancer?

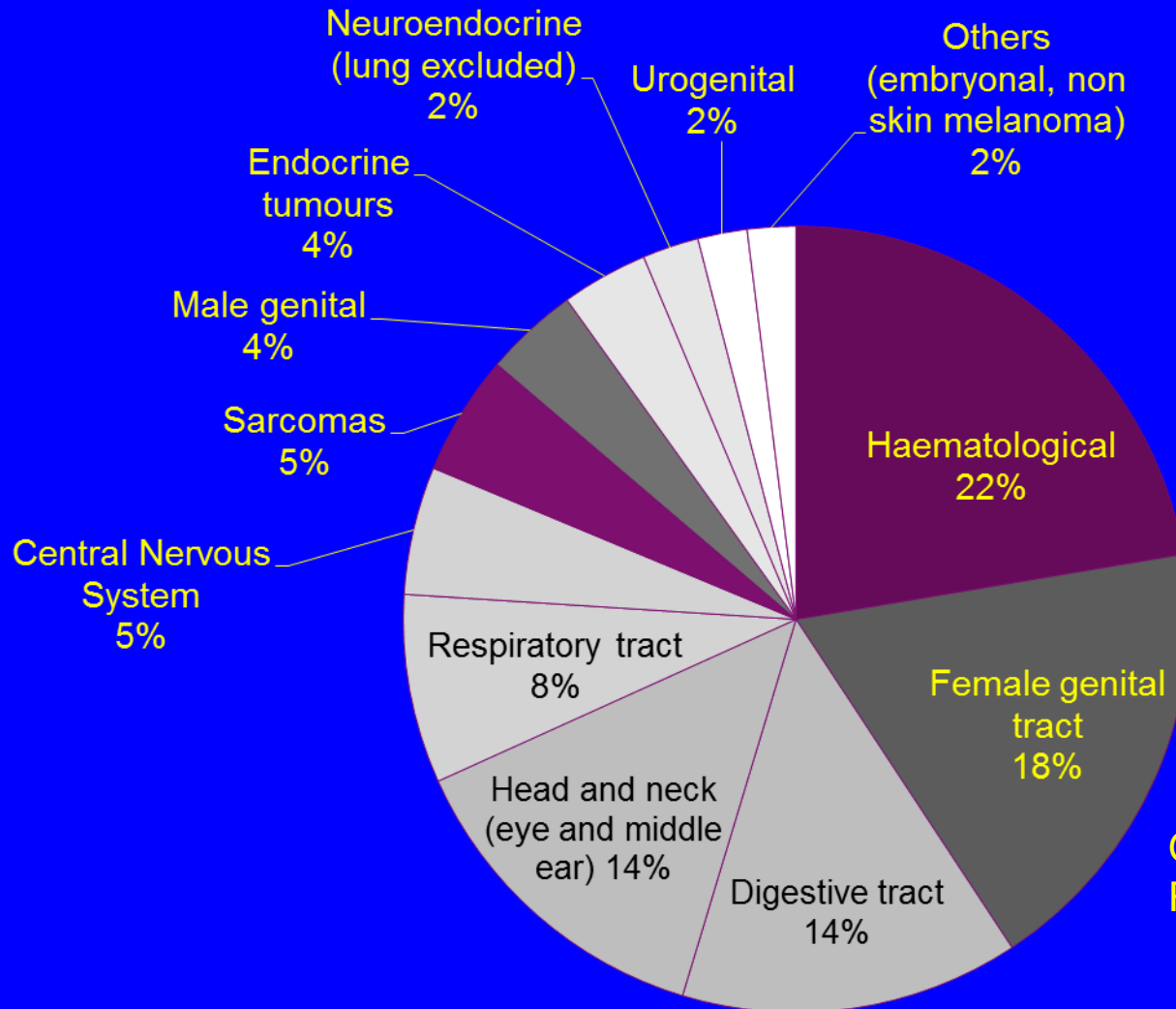
Who will support and help us navigate the journey?

Rare Cancers

some of the challenges...

- Access to therapies
- Access to clinical trials
- Varying treatment standards
- Not enough research into better treatments
- Not enough support for patients and caregivers

Rare cancers in Europe are defined by the RARECARE initiative as those cancers with an incidence of less than 6 people in 100,000 per year.



Graph courtesy of the RARECARE project

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Rare cancers are not so rare: The rare cancer burden in Europe

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ABSTRACT

Purpose: Epidemiologic information on rare cancers is scarce. The project Surveillance of Rare Cancers in Europe (RARECARE) provides estimates of the incidence, prevalence and survival of new cancers in Europe based on a new and comprehensive list of these diseases. **Materials and methods:** RARECARE analysed population-based cancer registry (CBR) data on European patients diagnosed from 1988 to 2002, with vital status information available up to 31st December 2003 (latest date for which most CBR had verified data). The mean population covered was about 162,000,000. Cancer incidence and survival rates for 1995–2002 and prevalence at 1st January 2003 were estimated.

Results: Based on the RARECARE definition (incidence <6/100,000/year), the estimated annual incidence rate of all new cancers in Europe was about 108 per 100,000, corresponding to 541,000 new diagnoses annually or 22% of all cancer diagnoses. Five-year relative survival was on average worse for rare cancers (47%) than common cancers (65%). About 4,300,000 patients are living today in the European Union with a diagnosis of a new cancer, 24% of the total cancer prevalence.

Conclusion: Our estimates of the rare cancer burden in Europe provide the first indication of the size of the public health problem due to these diseases and constitute a useful base for further research. Centres of excellence for new cancers or groups of rare cancers could provide the necessary organizational structure and critical mass for carrying out clinical trials and developing alternative approaches to clinical experimentation for these cancers.

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1. Introduction

There is no internationally agreed definition of rare cancers. In Europe rare diseases are often defined as those with a

prevalence of <50/100,000.¹ In the US, the Orphan Drug Act defined rare diseases as those affecting <200,000 persons.² However, a recent analysis of rare cancers in the US employed the definition of <15 incident cases per 100,000 per year.³

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Paper in the *European Journal of Cancer* by the RARECARE Working Group (Gemma Gatta, Jan Maarten van der Zwan, Paolo G. Casali, Sabine Siesling, Angelo Paolo Dei Tos, Ian Kunkler, Renee Otter, Lisa Licitra, Sandra Mallone, Andrea Tavilla, Annalisa Trama, Riccardo Capocaccia)

Rare Cancers – Some Statistics

- Rare cancers are cancers with an incidence of less than 6 people per 100,000 per year.
- There are over 180 different types of rare cancers.
- Rare cancers represent in total about 20% of all cancer cases.
- All cancers in children are rare.
- Each year, more than 500,000 people in the EU are newly diagnosed with a rare cancer.
- There is evidence that five-year relative survival rates are worse for rare cancers than for common cancers.
- 53% of all cancer deaths in the UK are from rare and less common cancers.



Rare Cancers

more challenges...

- Late or incorrect diagnosis
- Lack of access to clinical expertise
- Not enough clinical trials
- Lack of interest in developing new therapies due to market limitations
- Not enough registries and tissue banks

The solutions to these challenges need to address:

- Regulatory barriers
- Methodological barriers
- The need for centres of expertise and European reference networks
- Access to care
- Education of health professionals
- Access to information on rare cancers

Rare cancers

some examples of good practice

HEADSMART

speeding up the diagnosis of children and young people with brain tumours

OVACOME

Symptom tracker in the BEAT campaign charts the development of symptoms and helps patients communicate the results to GPs

LIFE RAFT GROUP

GIST Collaborative Tissue Bank – a unique partnership between researchers and patients

UK NATIONAL CANCER INTELLIGENCE NETWORK (NCIN)

Supporting patient empowerment and closer engagement with their own care

> 4,000,000

**Over four million reasons
why we need to improve
the rare cancer journey**

**Every morning, we should all
ask ourselves:
What can we do for rare cancer
patients today?”**

**And every evening, we should ask:
“Have we done enough?”**

Thank you for listening

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