



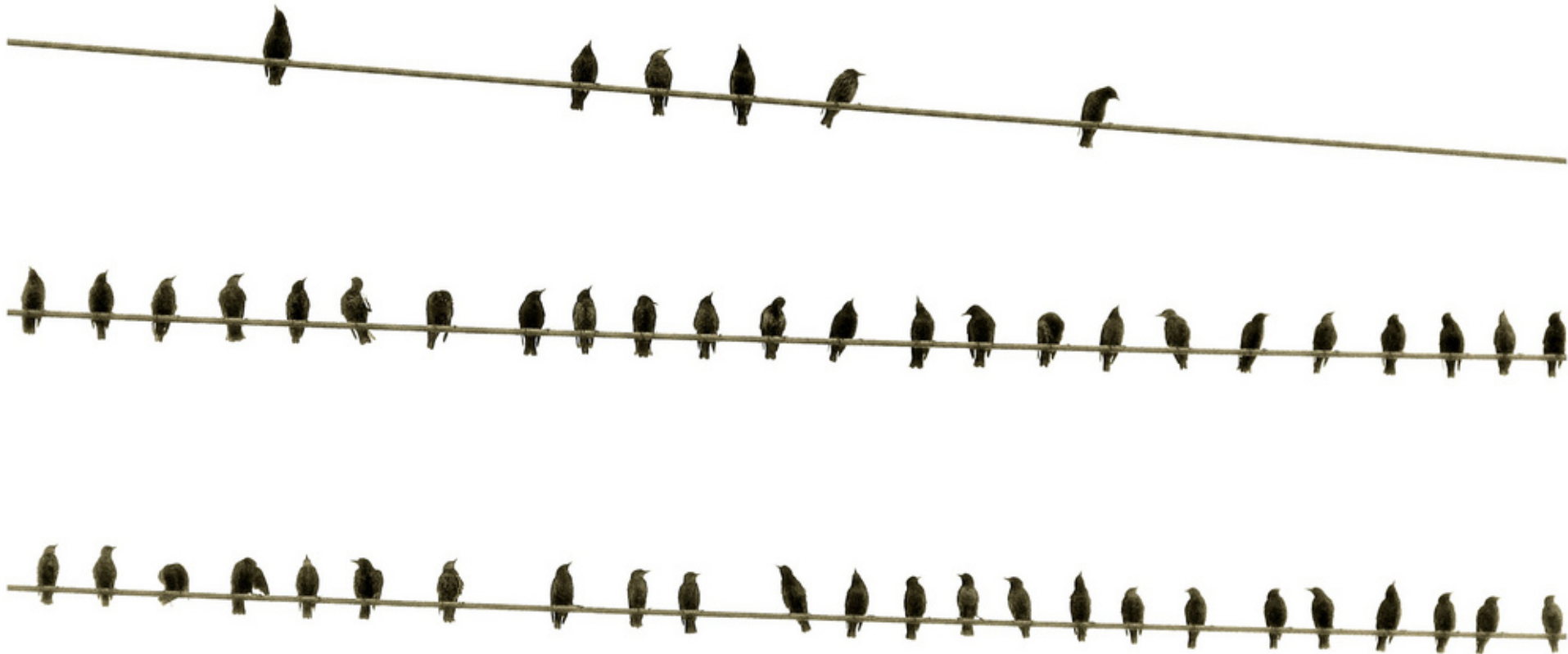
Rare Cancers in Europe: Challenges and Solutions

ESMO Patient Seminar, 28 Sept 2014

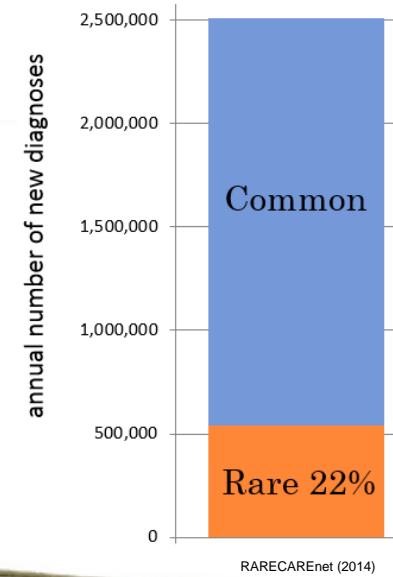
Jan Geissler

Co-founder, CML Advocates Network / Vice President, Leukemia Patient Advocates Foundation
Director, European Patients' Academy on Therapeutic Innovation (EUPATI)
Member, EU Expert Group on Rare Diseases, EC Expert Group on Cancer Control

**1 in 3 Europeans will get cancer
in their lifetime**



Every fourth cancer case is rare: Patients feel quite left alone.



Specific challenges for patients with rare cancers

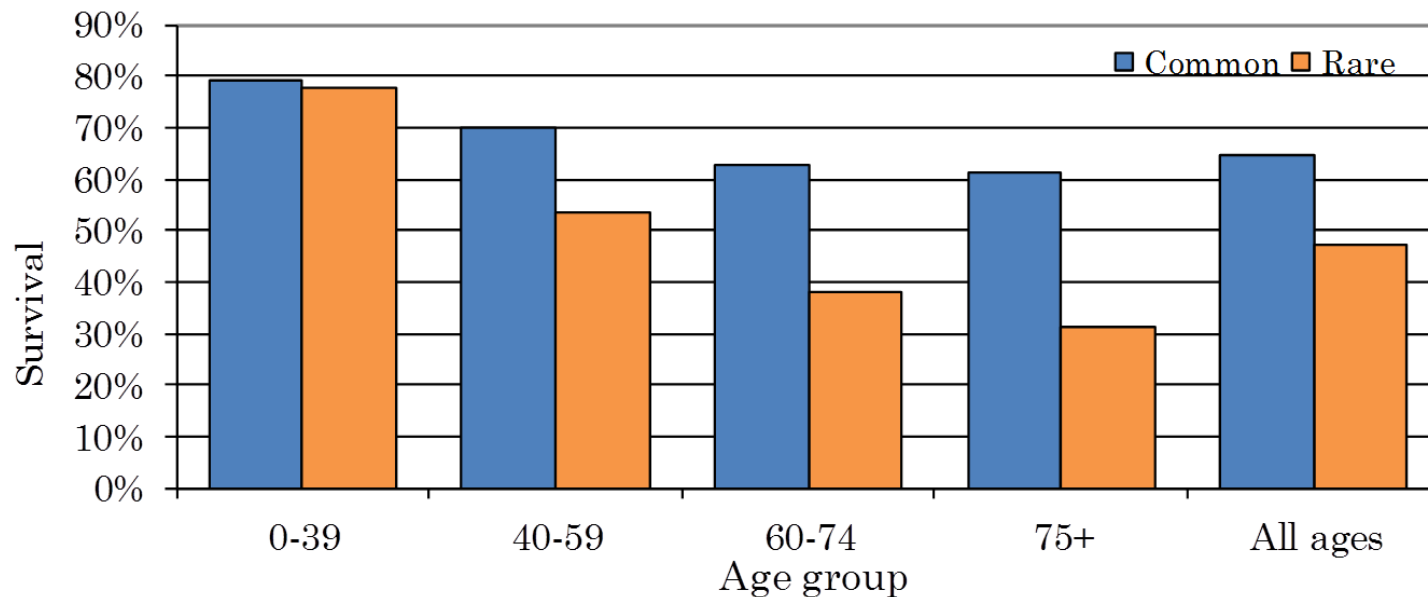
1. **Prevention and screening** mostly irrelevant
2. **Late or incorrect diagnosis** very common
3. **Lack of access to clinical expertise**
and local experts
4. **Lack of information & local patient groups**
5. **Facing stigma and inequity**
6. **Slowness & lack of research**
7. **Lack of appropriate therapies**



“Success stories“ available only to small numbers of rare cancers

Patients in urgent need of better treatments

5 YEAR RELATIVE SURVIVAL FOR RARE AND COMMON CANCERS IN EU27 BY AGE GROUP



RareCare (2012)

Rare Cancers – some solutions...



Specialize!

Best to be treated in an experienced center of excellence

- Misdiagnoses common before diagnosed appropriately
- Number of „cases“ in a center, conduct of studies is indicator for up-to-date expertise and treatment outcome

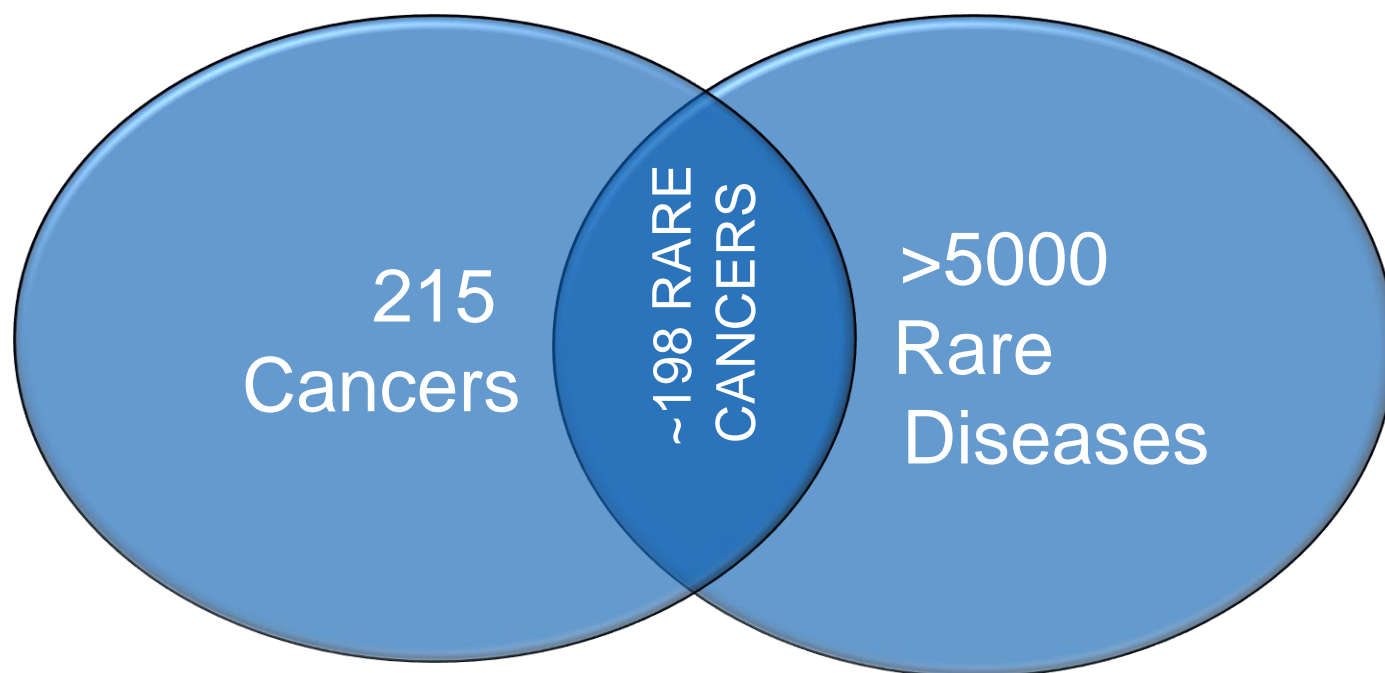


Source: Standard therapy in ,FIGO I-IIA: Study- vs Non-Study clinic, German Quality program QIII 2001 AGO OVAR

It's time to join forces!

Cancers, rare cancers, rare diseases

- 198 rare cancers are often lost between 17 common cancers and >5000 rare diseases
- Health policy is mostly not indication-specific, but supports orphan conditions



Understand EU policy and what it can do for rare cancers!

e.g. Patients' Rights in Cross-Border Healthcare 2011/24/EU



- Clarity and legal certainty on access to diagnosis & healthcare in other EU Member States
 - Especially when condition requires particular expertise or resources (e.g. rare diseases)
- National contact points
- Rules for reimbursement
- Procedural guarantees
- Prior authorisation system & reasons to refuse & time limits
- Cooperation between health systems

Strengthen patients' organisations as ,navigators' for patients

- **Most „official“ information portals fail on rare cancers:** Budget for the "Top 17".
- **Patient organisations inform, help, support** on disease, therapy, side effects, anxiety, clinical trials, research



Engage (as) patients in rare cancer research!

- ***"More needs to be done: rare cancers will never be a priority unless the patients make it one. Patients themselves must therefore play a larger role in driving forward the search for therapies. They are able to see connections that have eluded scientists."***



VOLUME 27 • NUMBER 18 • JUNE 1 2009

JOURNAL OF CLINICAL ONCOLOGY

PERSPECTIVES IN ONCOLOGY

To Make Progress in Rare Cancers, Patients Must Lead the Way

Amy Dockser Marcus

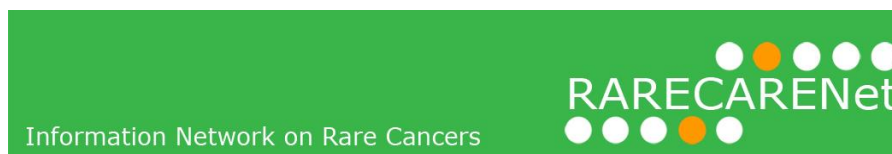
Submitted January 9, 2009; accepted February 3, 2009; published online ahead of print at www.jco.org on May 4, 2009.

In January, 2004, I flew to New Orleans, LA, to meet Andy Martin. He took me to the laboratory where he was working. A third-year medical stu-

dent. They recognized that when it came to SNUC, Andy was in many ways the expert on the disease. These physicians learned from the research he did,

Collaborate across borders and disciplines!

There are great opportunities.





Rare, but not alone.
Collaborate!

Jan Geissler

jan@cmladvocates.net

Twitter @jangeissler

PATIENT
ADVOCATES **IN**

NOT OUT