QUESTIONS AND ANSWERS

RARECARE Project

In 2007 the European Commission financed the RARECARE project to put numbers to a problem long known to exist

WHAT are rare cancers?
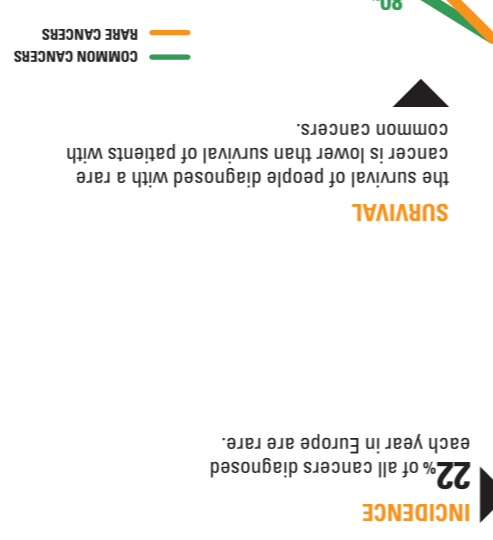RARECARE established a **NEW DEFINITION** of rare cancers based on incidence

Cancer is named **rare** when it is equal or less than 6 new cases per 100,000 persons in one year

WHICH cancers are rare?
RARECARE proposed a **NEW LIST** of rare cancers

The **RARECARE** list of 186 rare cancers is available on the project web-site

HOW MANY people are affected by rare cancers?
RARECARE estimated the **NUMBER OF NEW CASES** occurring each year and the **NUMBER OF PEOPLE** living with a rare cancer

RARITY BRINGS ABOUT A WIDE RANGE OF DIFFICULTIES
- Lack of information
- Misdiagnosis and delay in diagnosis
- Lack of scientific knowledge
- Lack of appropriate therapies and clinical expertise

Data available at **www.rarecare.eu**

RARE CANCERS ARE NOT SO RARE

RARECARE Project

In 2011 RARECARE published the burden of rare cancers in Europe for the first time

INCIDENCE
2,500,000 new cancers are diagnosed each year in Europe
1 out of 5 is rare
22% of all cancers diagnosed each year in Europe are rare.

PREVALENCE
In Europe 4,300,000 people live with a rare cancer
16,500,000 people live with cancer
24% of all people living with cancer in Europe have a rare cancer.

SURVIVAL
the survival of people diagnosed with a rare cancer is lower than survival of patients with common cancers.

COMMON CANCERS — RARE CANCERS
80% — 68%
69% — 52%
65% — 47%
YEARS AFTER DIAGNOSIS: 1, 3, 5

INTERNATIONAL COLLABORATION

To address rare cancers challenges an International Collaboration is needed

RARECAREnet

RARECARE Project turned into **RARECAREnet** which is a network of organisations collaborating in research and in the identification of the appropriate solutions to address rare cancers difficulties pursuing the following objectives...

RARECAREnet

OUR MAIN OBJECTIVES

1. to collect and disseminate information on **updated epidemiological indicators** on the basis of 83 population-based Cancer Registries from 24 countries in Europe.

2. to describe the **healthcare pathways** for rare cancers.

3. to develop a **clinical database** on a sub-group of rare cancers.

4. to propose quality criteria for **centres of expertise** for rare cancers.

5. to list **centres of treatment** for rare cancers in Europe.

6. to support the identification of **European Reference Networks**.

7. to develop and disseminate **current clinical approaches** to rare cancers.

8. to increase **awareness** among general practitioners and pathologists about rare cancers.

9. to **disseminate information** tailored to the needs of patients and of all concerned stakeholders.

10. to **support patients' associations empowerment**.

In this general framework full of difficulties, there is always something useful that can be done

Visit us at
www.rarecarenet.eu

RARECAREnet

www.rarecarenet.eu

ASSOCIATED PARTNERS
- Fondazione IRCCS, Istituto Nazionale dei Tumori, Milan, Italy
- The University of Edinburgh, Scotland, UK
- Institut de Cancérologie Gustave Roussy, France
- Istituto Superiore di Sanità, Italy
- Integraal Kankercentrum Nederland
- European Cancer Patient Coalition
- National Oncology Hospital, Bulgaria
- Cancer Society of Finland – Institute for Statistical and Epidemiological Cancer Research, Finland
- Institute of Oncology Ljubljana, Slovenia
- National Cancer Registry Ireland

COLLABORATING PARTNERS
- Rare Cancers Europe (RCE)
- European Society of Surgical Oncology (ESSO)
- European Society for Medical Oncology (ESMO)
- European Organisation for Research and Treatment of Cancer (EORTC)
- European School of Oncology (ESO)
- European Cancer Organisation (ECCO)
- Institut National de la Santé et de la Recherche Médicale (INSERM)- Orphanet
- Centre Léon Bérard, Lyon, France
- EUROPEAN CANCER REGISTRY BASED STUDY ON SURVIVAL AND CARE OF CANCER PATIENTS (EUROCARE)
- Leukemia Patient Advocates Foundation
- European Partnership for Action Against Cancer (EPAAC)
- Cancer52, UK
- European Society for Radiotherapy and Oncology (ESTRO)

From **RARECARE Project** to **RARECAREnet**

RARECARE Project
An initiative to define and disseminate information about the burden of rare cancers in Europe

RARECAREnet

A network to provide comprehensive information on rare cancers to the COMMUNITY AT LARGE

PATIENTS' ASSOCIATIONS
ONCOLOGISTS
RESEARCHERS
HEALTHCARE PLANNERS
PATIENTS AND THEIR FAMILIES
GENERAL PRACTITIONERS

RARECAREnet

IS WORKING TO PUT RARE CANCERS ON THE MAP

● RARECAREnet ASSOCIATED PARTNERS
○ PARTICIPATING CANCER REGISTRIES

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European Commission