Information network on Rare Cancers

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Background
A previous project called RARECARE (Surveillance of rare cancers in Europe) was an initiative to define and disseminate information about the burden of rare cancers in Europe. RARECARE revealed that rare cancers are not so rare. In Europe 500,000 rare cancers are newly diagnosed each year. Which means that 22% of all cancer cases are rare cancers. Due to their low frequency, rare cancers pose particular challenges such as late or incorrect diagnosis, less access to appropriate therapies, and absence of clinical trials. Overall a lower relative survival is found in patients diagnosed with a rare cancer. RARECARE Project turned into RARECAREnet which is a network of organisations collaborating in research and the identification of the appropriate solutions to address rare cancers difficulties.

Objective
The RARECAREnet project aims at:
• building an information network to provide comprehensive information on rare cancers to the community at large (oncologists, general practisioners, researchers, health authorities, patients)
• promoting international collaborative groups to foster research on rare cancers
• identifying determinants of variations in survival across Europe
• supporting better health care planning and resource allocation for rare cancers
• empowering patients

Methods
Main actions based on cancer registry data:
• Provision of updated incidence, prevalence and survival estimates for rare cancers, based on the EUROHIS database, including EU cancer registry data
• Create wide consensus with the major EU scientific societies and patient organisations on quality criteria for centres / networks of expertise for rare cancers
• High resolution studies on selected rare cancers (sarcomas, testicular cancer, head and neck cancer and GEP-NETs), to determine the health care pathway of these cancers
• Identification of centres of expertise for rare cancers in collaboration with patient organisations

Results
Quality criteria for centres / networks of expertise were developed in a multidisciplinary setting, resulting in indicators focusing on the three main pillars within the patient pathway:
1. Diagnosis
   o Use of specific imaging
   o Stage at time of diagnose
   o Pathology report (reviewed)
   o Time between pathological confirmation and first treatment
2. Treatment
   o Referral pattern
   o Free margins after surgery / number of revisions
   o Time between first treatment and adjuvant therapy
3. Follow-up
   o Vital status of the patient
   o Cause of death
   o Last date of follow-up

A high resolution study is put in place covering 4 national Cancer Registries and 11 regional Cancer Registries in Europe.

Final results will be published at our website: www.rarecarenet.eu

RARE CANCERS ARE NOT RARE

RARECAREnet supports rare cancers to be a political priority in the EU and EU member states, international collaboration to deal with the wide range of difficulties is essential.