

## FAVO The role of cancer patient organisations as advocates for people with rare types of cancer

### Il ruolo delle organizzazioni di pazienti oncologici in difesa di chi è affetto da tumore raro

Federazione italiana delle associazioni di volontariato in oncologia (FAVO)

Italian Federation of Volunteer-Based Cancer Organisations (FAVO) considers the data presented in this monograph to be very valuable and important to outline the burden of rare cancers in Italy, which weigh heavily on the national health budget, and provide a fundamental prerequisite to adequately support people who have to face an uncommon cancer diagnosis and treatment.

In 2010, 360,000 persons were diagnosed with cancer in Italy. Of these, 89,000 (25%) were diagnosed with a rare type of cancer. The monograph adds that the majority of rare cancers (139 out of 198) are very rare (incidence rate <0.5 per 100,000) and affect only 7,100 individuals, or about 2% of the total number of people with cancer. This is important, because low incidence is a major obstacle to conducting clinical trials to develop effective treatments.

This monograph includes another important result. Five cancers considered rare on the basis of the European incidence rate are not rare in Italy (diffuse large B-cell lymphoma, multiple myeloma, hepatocellular carcinoma or HCC, larynx and thyroid cancer). These 5 cancers affect around 30,000 individuals in Italy and do not seem to be as critical as the other types, thereby presenting a countertrend compared to European figures. Rare cancers imply late diagnosis and hence late treatment, limited access to appropriate treatments, including compassionate use of drugs, reduced number of centres with specialised experience and expertise, lack of information on the disease and difficulties to carry out clinical trials on the efficacy of a new treatment.

FAVO provides information on the available centres with specialised experience and expertise in rare cancers both in Italy and in Europe, and produces and disseminates information on diagnosis and treatment through ad-hoc designed materials (for more information, please call the toll-free number 800-903789, write to [info@favo.it](mailto:info@favo.it), or visit the website: [www.favo.it](http://www.favo.it)). FAVO has also played a major role in the performance of joint research projects supported by the Italian Ministry of Health and carried out in collaboration with the Fondazione IRCCS, Istituto Nazionale dei Tumori of Milan (Rare Cancers in Italy, Surveillance and evaluation of access to diagnosis and treatment – RITA2 project, Interaction Framework between patient advocacy groups and sarcoma cancer centres as a model for rare cancers).

FAVO has partnered with the European Cancer Patient Coalition (ECPC) within the RARECAREnet (Information Network on Rare Cancers) research project financed by the European Commission and coordinated by the Fondazione IRCCS, Istituto Nazionale dei Tumori of Milan. As part of this project, ECPC drafted a list of 144 rare cancer patient organisations in Europe with the aim to build a good network to support patients with rare cancers. The list, which is available on the RARECAREnet website (<http://www.rarecaren.net/rarecarenet/index.php/patient-organisations>), provides details such as name, country, contact details, and website of each organisation. ECPC also collected information materials on most rare cancers identified by RARECAREnet experts, thereby creating an online li-

brary (available on the RARECAREnet website) that patients can query to find information on diagnosis, treatment, and follow-up of any rare type of cancer. To help patients with rare cancers to deal with the numerous disease-related issues, FAVO has joined the Rare Disease Inter-Parliamentary Group chaired by Parliament member Mrs. Binetti, and used their connections with scientific societies, academia, scientific institutions, etc. to form a group of stakeholders. The result of this joint effort was a Rare Cancer Paper that Mrs. Binetti discussed in Parliament through a specific motion, soon followed by numerous others. All motions were approved unanimously by the Chamber of Deputies with the Government's consent.

The approved motions call on the Italian Government to:

- encourage initiatives aimed at ensuring continuity and institutionalisation of the Rare Cancer Network operation (for further information, please refer to «The Italian Rare Cancer Network», p. 116) and its inclusion in the National Health System;
- formalise a rare cancer list;
- initiate a pathway leading to the definition of rare cancer centre accreditation criteria in order to centralise treatment locally and serve as an interface between treatment centres within the specific joint networks to achieve maximum effectiveness;
- set up a rare cancer working group under the Ministry of Health with the participation of cancer registries and cancer patient organisations;
- facilitate rare cancer patient access to compassionate use of drugs through amendment of Ministerial Decree May 8, 2003 (*Therapeutic use of a drug undergoing clinical trial*);
- invest on clinical research on rare cancers and their inclusion in public health programs;
- make sure that representatives from rare cancer patient organisations with recognised experience and expertise are involved in all rare cancer forums;
- facilitate patient referral to the Network centres in the early treatment phases through a widespread information system in which cancer patient organisations play a leading role;
- facilitate access to off-label drugs through the Italian Agency for Drugs's (AIFA) research fund, even by involving patients' caring physicians, to ensure ongoing, effective care, even though, so far, certain, definitive solutions are lacking.

For rare cancer patients, the activation of cross-border health care is extremely important. To this end, the Cross-Border Directive set as a priority for rare disease and rare cancers the creation of European Reference Networks (ERNs), to connect centres with specialised experience and expertise in specific diseases from the various Member States. ERNs can help treat patients with rare diseases for whose treatment it would be impossible to establish new treatment centres in all European Member States. ERNs can facilitate patient mobility among the Member States, above all to allow them to have access to particularly complex or specific health services for the treatment of rare diseases, including rare cancers.