

Teleconsulting to bring specialised expertise in rare cancers across Europe

February 8 2018

The ESMO Sarcoma & GIST Symposium in Milan, Italy has seen a record attendance of almost 450 international experts gathered to discuss the latest developments in the management of this rare condition, representing less than 1% of all adult solid cancers.

For the first time this year, the Symposium has been held in an improved context for rare cancer [patients](#), thanks to EURACAN, the European Reference Network (ERN) for rare adult solid cancers, which was launched in March 2017.

Rare tumours such as sarcomas pose additional challenges over and above those faced by patients with more common cancer types, because their low prevalence makes it difficult for physicians in the community to acquire significant experience in diagnosis and treatment. Similarly to other rare diseases, translational and clinical research in this field is hampered by the low numbers and heterogeneity of cases. As a result, access to and development of new drugs can be challenging.

"The lack of information about the disease, limited treatment options and, until now, the low visibility of and insufficient attention paid by health policies to these [rare cancers](#), are all factors that significantly affect patient outcomes," said Ornella Gonzato, President and Founder of Associazione Paola, a national association in Italy that aims to improve both treatments and quality of life for sarcoma patients, by providing them with information and referrals to centres with appropriate clinical expertise.

"Receiving a tumour diagnosis is certainly never easy, but for sarcoma patients, receiving a diagnosis at all is particularly difficult. The symptoms, due to the fact that they are not specific during the early stages, are often not recognised or misinterpreted," said Gonzato.

This is precisely what happened to Gloria, a young woman who first saw her doctor because of pain and swelling in the knee: "At the time, Gloria played tennis at an almost competitive level. Her physician prescribed anti-inflammatory drugs and rest, analysing the problem as a trauma caused by intense physical activity," Gonzato reported.

Several months, a battery of tests and various drug prescriptions later, she had seen three different doctors and the situation still had not improved. "The pain and swelling in her knee did not subside. Gloria's quality of life deteriorated," said Gonzato. "Her habits had to change. In addition to her knee pain, she also started suffering from intermittent fever."

By this time, seven months had passed: "That's when she decided to search for information online and found the Associazione Paola website. Reading the descriptive sheets on musculo-skeletal diseases, she recognised some of her symptoms," said Gonzato. "She contacted the association to tell her story, and was immediately sent to the centre with the appropriate clinical expertise."

After another series of tests, Gloria's disease could finally be given a name: Ewing's sarcoma. "Gloria now faces a long and complex therapeutic path, but she is supported by the right medical expertise. Her relationship with Associazione Paola has continued, in order to exchange clinical information and keep track of her progress," Gonzato reported.

According to Gonzato, many of the requests submitted to the association revolve around the question: "Where can I go to obtain the correct

diagnosis and the appropriate treatment?" Fortunately, Gloria was able to find a reference centre for her disease in her home country of Italy. For many other patients throughout Europe, however, the relevant expertise in their specific condition is often held by specialised facilities a lot farther away.

At a European level, Rare Cancers Europe, in which ESMO is a key partner, has long been committed to providing better support to rare cancer patients: its contributions to the creation of ERNs like EURACAN have been a major step in this direction. ERNs, which were conceived by the European Commission, are networks of hubs, based on the voluntary collaboration of reference institutions across Europe tackling rare cancers. They are characterised by a high concentration of knowledge to help patients obtain timely diagnosis, receive appropriate treatment and access innovative clinical studies.

In the countries of the European Union, 198 rare tumour types account for as much as 24% of annual cancer diagnoses and affect the lives of more than 4.3 million people. (6) Anna Maria Frezza is a medical oncologist at the Istituto Nazionale Tumori in Milan, (7) the centre coordinating the sarcoma domain within the EURACAN network: "For soft tissue sarcomas, as for the majority of rare cancers, ensuring a high quality of care and a multidisciplinary approach to patients - from pathological diagnosis all the way to surgery - is a major issue," she said.

"Establishing reference centres for rare cancers, which pool resources and share best practices within their network, was the first step towards addressing this problem," Frezza explained. However, asking patients to travel in order to seek treatment is not ideal - mainly because of the negative impact of migration on patients' quality of life and financial resources.

"The key here was to evolve past the reference centre logic towards the

concept of a referring network (8), where the reference centres would serve as hubs that provide a wide range of services and concentrate experience in a particular field, while the connection with established national networks would ensure wide geographical coverage," she said. The EURACAN network's primary goal is to improve assistance for rare [cancer](#) patients, limiting migration and reducing inequalities in outcome across EU countries. (9) In this framework, the core business of EURACAN reference centres will be teleconsulting: the idea behind this information technology platform, currently under development, is that the expertise of the reference centres will be made available to all healthcare providers wherever they are, saving patients from having to travel for treatment.

"In addition to providing medical assistance, ERNs are also committed to fostering research, promoting public health surveillance, as well as ensuring education for physicians and information for patients," said Frezza.

More information: Gemma Gatta et al. Burden and centralised treatment in Europe of rare tumours: results of RARECAREnet—a population-based study, *The Lancet Oncology* (2017). [DOI: 10.1016/S1470-2045\(17\)30445-X](#)

G. Gatta et al. Epidemiology of rare cancers and inequalities in oncologic outcomes, *European Journal of Surgical Oncology* (2017). [DOI: 10.1016/j.ejso.2017.08.018](#)

Provided by European Society for Medical Oncology

Citation: Teleconsulting to bring specialised expertise in rare cancers across Europe (2018, February 8) retrieved 1 May 2024 from <https://medicalxpress.com/news/2018-02-teleconsulting->

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