

Forgotten cancers: Patients are paying a high price

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Thousands of patients with rare "forgotten cancers" are paying a high price because doctors lack awareness of their conditions, according to a speaker at the 4th ESMO Conference on Sarcoma and GIST.

Personal tragedies often unfold as men and women who have one of a rare type of cancer known as sarcoma are repeatedly misdiagnosed and given inappropriate therapies, patient advocate Markus Wartenberg will tell the conference in Milan, Italy, from March 9-11.

Now in its fourth year, the ESMO Conference has become an important event for the international community of experts who research and treat sarcomas.

Sarcomas are a group of more than 60 different tumor types that affect bone, muscle, fat, [blood vessels](#) and other tissues. Each of these distinct cancers is individually quite rare, however together they affect about 10,000 people in Europe each year.

"One patient I spoke to last week had been given seven different diagnoses before he was finally correctly diagnosed," says Wartenberg, a representative of the German patient organization Das Lebenshaus.

"He is 42, and is the father of two small children. The [correct diagnosis](#) came far too late. If he had come sooner to a qualified center, maybe his prognosis would be totally different."

Each of the many different sarcomas requires particular treatment, meaning specialized multidisciplinary care is vital to ensure the best possible outcomes.

"The general problem in many countries is that many sarcoma patients are treated inappropriately, and there is not the real awareness about this group of diagnoses and sets of treatments," says Wartenberg.

Specialized sarcoma centers are an important part of delivering that care. Where patients can access those specialized centers, their chances of a good outcome are improved, he says.

Beyond diagnosis and access to care, sarcoma patients also need new, more effective therapies. "The ESMO conference brings together cancer experts to share the latest findings about the biological mechanisms leading to sarcomas," says Prof Jean-Yves Blay, conference co-chair.

"Because sarcomas are rare, the initial management is often inadequate," Prof Blay says. "Innovations that improve the rates of patient referral to expert centers could result in some cures being more easily achieved."

"However, because sarcomas have well-characterized molecular alterations, they are an ideal model for developing new therapies," Prof Blay adds. "The more we understand about the molecular basis of these diseases, the easier it will be to develop focused therapies. The knowledge we derive from this work could also advance the development of targeted therapies more widely in [cancer](#)".

More than 300 experts will attend the conference, where they will hear about developments in surgery, advances in molecular classification of sarcomas and the shift toward personalized medicine, said co-chair Prof Paolo Casali, ESMO Board member.

"Novel treatments are now emerging for a large number of sarcoma types," he said. "The molecular mutations that underlie many sarcomas are relatively simple, making them ideal candidates for developing targeted therapies that directly address the molecular basis of the disease."

Provided by European Society for Medical Oncology

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