



Sarcoma  
Patients  
EuroNet

## PRESS RELEASE

### **Sarcoma Patients EuroNet's policy paper "Sarcoma Patient Pathway Analysis and Recommendations for Service Development" awarded Best Abstract by European CanCer Organisation (ECCO)**

**Presentation of the paper by co-author and SPAEN's co-chair Estelle Lecointe-Artzner, during a Plenary Session on the ECCO Congress 2017 on Saturday, January 28 at 9:55, room Veronesi.**

*Wölfersheim/Germany, January 27, 2017 – Sarcomas are a rare and heterogeneous group of cancers affecting connective soft tissue and bone. More than 50 sub-types are known. However, sarcomas only account for about 1% of all cancer diagnoses. Due to the rareness of the disease, misdiagnosis, inappropriate and non-expert treatment are common. This policy paper "Sarcoma Patient Pathway Analysis and Recommendations for Service Development", written by Sarcoma Patients EuroNet (SPAEN) now gives a clear statement of what patient advocates expect sarcoma treatment to look like, how service structures should develop to respond to patient needs, and how national and international referral practice should evolve. It was awarded "Best Abstract" by the scientific committee of the European CanCer Organisation (ECCO) and will be presented orally in a Plenary Session on Saturday, January 28, 2017 on the annual ECCO congress. The paper was written by SPAEN's Honorary President Roger Wilson and SPAEN's co-chairs Estelle Lecointe-Artzner and Markus Wartenberg.*

"Sarcoma patients have to deal with a number of issues which affect their survival", says Estelle Lecoint-Artzner, SPAEN co-chair and co-author of this paper. "Among them are late or misdiagnosis, surgery done by non-experts, high rate of morbidity (especially in metastatic settings), high potential for recurrences and lack of effective treatment in advanced settings". More than 50% of all sarcoma patients are diagnosed with advanced cancer, some at diagnosis, some after a decade or more of otherwise undisturbed survival. Prognosis for this group is poor and treatment options are limited.

"We identified a number of areas of primary concern – all of them equally important", explains SPAEN's Honorary President Roger Wilson, lead author of the policy paper. "They include diagnosis, specialist surgery, referral networks, patient rehabilitation, access to clinical trials, advanced disease,

second opinions and specialist centres.” The paper “Sarcoma Patient Pathway Analysis and Recommendations for Service Development”, describing the optimum pathway of care and treatment in sarcomas from a patient’s point of view, has been developed in response to several national and international requests. These were seeking a patient perspective either to complement the views of specialist doctors or to provide a framework for a national plan in the absence of specialist viewpoints.



One of SPAEN’s main objectives is the identification of problems, challenges, access issues and unmet medical needs in sarcomas and the search for solutions to improve the situation for patients and their carers. “One step on the way to achieve this goal is to clearly describe the situation for sarcoma patients and to pinpoint needs and potentials for improvement and optimization in the treatment and care of sarcoma patients”, says Markus Wartenberg, SPAEN co-chair. “Our Sarcoma Policy Paper is a summary of our views – hoping that this will eventually improve survival and quality of life for sarcoma patients worldwide.”

*The paper will be presented by co-author and SPAEN’s co-chair Estelle Lecointe-Artzner, during a Plenary Session on the ECCO Congress 2017 on Saturday, January 28 at 9:55, room Veronesi. It is also available online on [www.sarcoma-patients.eu](http://www.sarcoma-patients.eu).*

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## BACKGROUND

### **About SARCOMAS**

Sarcomas are a diverse and rare group of malignant tumors, originating in supportive and connective tissues such as bones, tendons, cartilage, muscle, and fat. They only account for slightly more than 1% of all cancer diagnoses in adults and for nearly 21% of all solid malignant cancers in children and young adults. Approximately 50 distinct subtypes exist, defined by the type of cells they arise from. Basically, sarcomas can occur at any age and are not restricted to a specific location of the body. The rarity of the disease combined with the diverse number of subtypes can make sarcomas very difficult to treat correctly as well as to study.

### **About SPAEN**

Sarcoma Patients EuroNet Association (SPAEN) is an International Network of Sarcoma, GIST and Desmoid Patient Advocacy Groups. It was founded in April 2009 with the aim of extending information services, patient support and advocacy to patient organisations for the benefit of sarcoma patients across the whole of Europe and internationally. Acting in partnership with clinical experts, scientific researchers, industry and other stakeholders SPAEN is working to improve the treatment and care of sarcoma patients through improving information and support, and by increasing the visibility of sarcoma with policymakers and the public.

For more information please view the SPAEN website [www.sarcoma-patients.eu](http://www.sarcoma-patients.eu)