Sarcoma
Patients
EuroNet

PRESS RELEASE

Information, Education and Guidance in Sarcomas: New International Sarcoma Patients Online Platform launched

Wölfersheim/Germany, February 6, 2017 – Sarcoma Patients EuroNet (SPAEN) announced today the launch of the new International Sarcoma Patients Online Platform – a new website for comprehensive information and education, guidance and exchange about soft tissue sarcomas, bone sarcomas, gastrointestinal stromal tumours (GIST) and Desmoids. It aims to improve information about sarcomas in patients and their carers, but also among advocacy groups, healthcare professionals and the healthcare industry: credible, trusted, understandable and up-to-date.

Sarcomas are a very rare and heterogeneous group of cancers affecting connective soft tissue and bone. They account for slightly more than 1% of all cancer diagnoses with more than 50 subtypes currently known. “Because sarcomas are so rare, misdiagnosis, inappropriate and non-expert treatment are common”, says Markus Wartenberg, co-chair of Sarcoma Patients EuroNet (SPAEN). “This can tremendously affect outcomes for patients. We therefore see the need for more information about sarcomas which will hopefully lead to earlier diagnosis and an improved survival. With the launch of our new online platform, we are now taking one very important step towards achieving this goal.”

The main objectives of the new platform www.sarcoma-patients.eu are to provide comprehensive information and education as well as to offer guidance for sarcoma patients and their carers – not only in English, but also in a variety of other languages as well. “Many patients don’t speak English, let alone medical English, well enough to understand a lot of information currently available about the disease, treatment options or ongoing studies. However, this a key precondition to take responsibility for oneself”, explains Estelle Lecointe-Artzner, co-chair of SPAEN. “We want to put patients in Europe and around the globe in the position to understand what they are dealing with and to advocate for themselves for improved treatment and care. That is why we are working towards making basic information and, in the future, more specific information about sarcomas available in different languages."

While knowledge of the disease and the treatment options are important the possibility of participating in a clinical trial can be helpful, if not life-saving, for those suffering from such a rare disease as sarcomas. The new International Sarcoma Patients Online Platform therefore offers background information about clinical studies as well as information about selected currently open trials in a patient-friendly way.

The next major step is to develop the new platform to become a tool for support, guidance and exchange among the SPAEN member groups. "For rare diseases, it is of the utmost importance to unite across borders and speak with one voice", say Markus Wartenberg. "Our member groups are very active in their respective countries and we can all learn from each other's expertise and experience. The new platform will be another tool to facilitate this international cooperation."
The new platform can be accessed on www.sarcoma-patients.eu.

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See us on **facebook**: www.facebook.com/Sarcoma-Patients-EuroNet-SPAEN-150381014994411/?ref=bookmarks

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BACKGROUNDER

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