Sarcoma Patients EuroNet

PRESS RELEASE

Sporadic Desmoid-type Fibromatosis: Update on management recommendations now published in "Annals of Oncology"

Wölfersheim/Germany, October 12, 2017 – Sarcoma Patients EuroNet (SPAEN) and the sarcoma experts from the European Organisation for Research and Treatment of Cancer (EORTC) Soft Tissue and Bone Sarcoma Group (STBSG) announced today, that the update on the position paper on the management of Sporadic Desmoid-type Fibromatosis has been published and printed in the October issue of "Annals of Oncology". To date, there are only limited well-established or evidence-based treatment approaches available for this disease. Therefore, a first consensus paper has been developed by the European Desmoid Working Group in 2015. It has now been updated, with a specific focus on new findings regarding the prognostic value of mutational analysis and new systemic treatment options. The paper has also been accepted for oral presentation during the annual conference of the "Connective Tissue Oncology Society" (CTOS) which will be held November 8-11, 2017 on Maui, Hawaii.

"Desmoid-type fibromatosis (DF) is a very rare disease: we see only 5-6 cases per 1 million per year", explains Professor Bernd Kasper, Mannheim University Medical Center, Germany and lead author of the updated consensus paper. DF arises in the deep soft tissues and does not spread among the body (metastasize). However, it is locally aggressive and its clinical course is often unpredictable. "Currently, we only have limited treatment options with a low level of evidence available", says Professor Kasper. "That is why it is so important to provide recommendations on diagnosis, imaging and treatment strategies for this rare disease."

The updated paper is a result of a roundtable meeting of sarcoma experts from the European Organisation for Research and Treatment of Cancer (EORTC) Soft Tissue and Bone Sarcoma Group (STBSG) and patients and patient advocates from Sarcoma Patients EuroNet (SPAEN). It not only gives recommendations on disease management, but also includes the patients' perspective. "For us as patients, it is very important to stress that DF cannot be treated like any other cancer", says

Christina Baumgarten, patient representative of SOS Desmoid Germany and board member at SPAEN. “We often experience that DF is classified as benign and patients are sent home without being aware that DF tends to recur. Doctors need to know about DF, but diagnosis and treatment belong in experts’ hands.”

Acknowledging the work both experts and patient representatives have put into the consensus paper update, the Connective Tissue Oncology Society (CTOS) has selected the abstract for oral presentation during their annual meeting in November in Maui, Hawaii. Professor Kasper will be holding the presentation in the “Special Session 2 - Trials/approaches in Rarer Sarcomas” on November 10, 2017 from 8:00 to 9:45 am at the Grand Wailea Resort, Maui, Hawaii.

For more information, please visit our website on www.sarcoma-patients.eu. The “Update on management recommendations for Sporadic Desmoid-type Fibromatosis” is accessible here.

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B A C K G R O U N D E R

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