



Sarcoma Patients EuroNet - Newsletter No. 3/2018

Dear SPAEN members and friends,

The sarcoma community is growing: SPAEN is now a strong network for sarcoma, GIST and desmoid PAGs with **41 member groups in 23 countries on all 5 continents**. And we are in close contact to even more patient groups in the world.

This is really encouraging, considering the tasks we (still) have ahead of us: From information and education for patients to asking the right questions in research to – at one point – ultimately help find a cure for these diseases. We can only do this together, combine our strengths and speak out loud with one, unified voice! The good thing is: We are on a very good way.

Thanks to all those dedicated people who spend their time, energy and passion to our common cause and to help others in need. Your work is much appreciated, you help make the world a little better, every day. **Let's keep on, together and stronger than ever!**

The SPAEN Board of Directors & Team



THE MANAGEMENT OF SARCOMA PATIENTS ACROSS EUROPE

"What are the key gaps in research, policy and practice in sarcoma care?"



The Sarcoma Policy Checklist, originally launched in 2017, has now been published in BMC Cancer. It was developed with the support of SPAEN and the German and French organisation Das Lebenshaus e.V. and Info Sarcomes, respectively. Check it out [here](#).

STUDY REGISTRY: CHECK FOR CURRENTLY RECRUITING

Taking part in a clinical trial can be a good choice but it is often hard to find a clinical trial that is right for you. Please check our website some of the clinical trials available worldwide and find some highlights [here](#).

- **The DOREMY Trial:** This study tries to answer the question, if a reduced dose of preoperative radiotherapy (radiotherapy before



surgery) in Myxoid Liposarcomas from 50Gy to 36Gy is equally effective than the standard dose of 50Gy. Find out [more](#).

- **The Invictus Trial:** This study assesses the safety and efficacy of a novel drug – a KIT and PDGFR α kinase switch control inhibitor called DCC-2618 – in patients with advanced GIST who have been treated with other anticancer therapies – incl. imatinib, sunitinib, regorafenib – before. More info [here](#).
- **REGOBONE:** This study assesses the safety and efficacy of regorafenib in patients with metastatic bone sarcomas (osteosarcoma, Ewing sarcoma of bone, chondrosarcoma or chordoma). It is only available in France. More info [here](#).



PROMS PUT PATIENTS AT THE HEART OF RESEARCH AND CARE



The need to give greater weight to patients' own assessments of treatment impacts is increasingly accepted in principle. Putting it into practice will require a lot of hard work. Read Simon Crompton's [article in Cancer World](#) and find out more about SPAEN's Honorary President Roger Wilson's thoughts about it.

OLARATUMAB IN SOFT TISSUE SARCOMA

In July 2016, a major breakthrough was achieved in the treatment of soft tissue sarcoma: the selective PDGFR α inhibitor olaratumab showed a survival benefit in combination with doxorubicin in advanced soft tissue sarcoma for the first time in more than 20 years.

But where do we stand now? [This article](#) summarizes what we know and don't know about olaratumab.

PERSONALIZATION OF REGORAFENIB TREATMENT IN METASTATIC GIST

Adjustment of dosing or treatment personalization is extremely important in everyday clinical practice to reduce the frequency or severity of adverse events and to avoid early treatment discontinuation. This also accounts for Regorafenib in GIST. Find out [more](#).

SORAFENIB IN DESMOID TUMOURS

Interim results from a randomized clinical trial for patients with desmoid tumours or aggressive fibromatosis (DT/DF) show that sorafenib extended progression-free survival compared with a placebo. Read more [here](#).

DASATINIB IN ADVANCED GIST

Does Dasatinib have an effect in a subset of imatinib-refractory GIST? It might. [Read more](#).



SURVEY FOR GIST PATIENTS: LONG-TERM NEGATIVE EFFECTS DURING TKI TREATMENT

Our partner organisation GIST Support International is currently conducting a survey on long-term negative effects during TKI treatment in GIST patients, together with the University of Pittsburgh, USA. More information can be accessed [here](#). If you are a GIST patient, please support this research and fill out the questionnaire!



WEST AUSTRALIAN SARCOMA AWARENESS WEEK

The Australian patient advocacy group “Sock it to Sarcoma” will hold the 5th West Australian Sarcoma Awareness Week from June 18-24, 2018. The programme can be accessed [here](#).



CHORDOMA COMMUNITY CONFERENCE: VIDEOS & HIGHLIGHTS

The 2018 International Chordoma Community Conference was held in March 2018 by the Chordoma Foundation. Videos & highlights from from the conference are now available on the [website](#).



NEW SARCOMA CLINICAL TRIALS HUB IN UK

[Sarcoma UK](#) has recently launched a [clinical trials hub](#) for people living with sarcoma in the UK. Patients and clinicians now have one central point for up-to-date information and advice on what trials are, how to take part and crucially, a list of current clinical trials in the UK.



NEW BROCHURE ABOUT SARCOMAS IN ITALIAN

Our Italian member organization “[Associazione Paola per i tumori muscolo-scheletrici. Onlus](#)” has published a new information brochure on sarcomas in Italian. It can be found and downloaded on our [website](#).



POSTGRADUATE COURSE ON SARCOMAS: WEBCASTS AVAILABLE!

The University of Milan and ESO European School of Oncology (both associated partners in EURACAN) have launched a programme of postgraduate courses on rare adult solid cancers for clinical oncologists. The course on sarcomas was held from 22 to 26 January 2018 and addresses adult-type soft tissue sarcomas, bone and pediatric sarcomas, GIST and sarcomas as rare cancers. All presentations are available [here](#) (webcast).



“STANDBY FOR DISRUPTION”

“As patients are we being too laid back? Should we be promoting technology based disruption in healthcare?” asks Roger Wilson in his blog post “Standby for disruption”. [Read more!](#)

LEIOMYOSARCOMA IN 2018

“Leiomyosarcoma in 2018 – where we are and where we need to go” – Dr. Breelyn Wilky is a sarcoma medical oncologist at Sylvester Comprehensive Cancer Center in Miami, Florida, USA. In one of her blog posts, she gave a very clear overview of the status quo in leiomyosarcoma and answered the most common questions by patients, carers and providers – please read [here](#).

LIDDY SHRIVER EARLY RESEARCH AWARD



The Liddy Shriver Early Career Research Award is intended to recognize, with an elite international award and lecture, an outstanding early-career researcher working in the sarcoma field. It is not primarily an award for future research, but an award based on track record of early achievement, and is intended to be international in scope. Read more [here](#).



PATIENT VOICE

FERTILITY, FAMILY PLANNING, SEXUAL DYSFUNCTION – AN UNFAIR TABOO?

Fertility preservation, family planning and sexual dysfunction during and after cancer treatment are unfair taboo topics and are not adequately addressed in counseling cancer patients – not sarcoma-specific, but very relevant for a lot of cancer as well as sarcoma patients. Read Jan Geissler’s view, founder of CML Advocates Network, [here](#).



UPCOMING EVENTS AND COURSES

ESMO 2018



The annual congress of the European Society of Medical Oncology (ESMO) will take place on 19 to 23 October in Munich, Germany:

<http://www.esmo.org/Conferences/ESMO-2018-Congress>

More information about the ESMO Patient Track and Travel Grants for patient advocates: <http://www.esmo.org/Conferences/ESMO-2018-Congress/Patient-Advocacy-Track>

CTOS 2018



The Annual Meeting of the Connective Tissue Oncology Society will be held November 14-17 at the Rome Cavalieri Hotel in Rome, Italy:

www.ctos.org



ABOUT SPAEN

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Sarcoma Patients EuroNet Association (SPAEN), the international Network of Sarcoma, GIST and Desmoid Patient Advocacy Groups, 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.

**Together We Can Make A Difference
For Those Affected By Sarcomas!**



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