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# SPAEN – NEWS

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

**Sarcoma Patients EuroNet - Newsletter No. 5/2018**

**Dear SPAEN members and friends,**

2018 is already coming to an end – **time to think about 2019!** That is why we held our SPAEN board meeting in October to plan our year 2019, the next steps and important issues in sarcomas from the patients' perspective. We'll have all our hands full next year and will keep you posted on our website, social media channels and of course our SPAEN newsletter – so stay tuned!



Warmly,  
**The SPAEN Board of Directors & Team**



## **9TH SPAEN ANNUAL CONFERENCE**

**SPAEN Conference 2018**  
**Save the date!**

**MILAN ITALY**  
**3-4 FEBRUARY 2018**



The next **SPAEN Annual Conference** will be held **February 1-3, 2019 in Athens, Greece**. We are looking forward to interesting presentations about relevant topics in sarcomas, GIST and desmoids, but also important advocacy and capacity building contents. Interested?

**Click [here](#) to see our preliminary programme and to register!**  
We are looking forward to seeing you in February 2019 in Athens!

## **WATCH OUR SPAEN WEBINARS ON YOUTUBE!**

You missed our **SPAEN Advocacy Campus webinars** with Dr Rick Haas, The Netherlands about **radiotherapy in soft tissue sarcomas (STS)** and Dr Robin Jones, UK, about experiences with **olaratumab in STS?**

No problem! We recorded them: **You can watch them whenever you want on our new SPAEN YouTube Channel.**



And we are currently planning our next webinars – please also watch our [website](#) for updates!



SPAEN member groups: Don't forget to apply now for our **SPAEN Advocacy in Action Award!** Why? Because it's so important to be loud: Patient advocacy ensures that people are heard, take action and ultimately improve situations, achieve changes or help to fulfil unmet medical needs.

**Deadline is December 1, 2018.**

Find more info [here!](#)



ESMO 2018



One of the most important European meetings for healthcare professionals in oncology was held in October in Munich: **The annual conference of the European Society of Medical Oncology (ESMO)**. Some interesting new data were presented in sarcomas and GIST:

- Outcomes for patients with **relapsed and unresectable osteosarcoma and Ewing sarcoma** remain poor, with no approved agents available in this setting. **Two phase II studies** have now evaluated the efficacy and safety of **cabozantinib** in advanced osteosarcoma and Ewing sarcoma. [Read more.](#)
- **DCC-2618** is a KIT and PDGFRa kinase switch control inhibitor that is currently tested in **advanced GIST**. The company Deciphera presented at ESMO promising **phase 1 clinical results**. [Read more.](#)
- Nanobiotix: Positive phase II/III results for NBTXR3 in soft tissue sarcoma presented at ESMO: Radiation therapy is a major pillar in sarcoma management, but efficacy is often limited by toxicity and outcomes in terms of tumour shrinkage are unsatisfying. **Nanoparticle therapy** might change that as it has the potential to **improve the outcomes of radiotherapy**. New data have been presented at ESMO: See the [company's own information](#) or watch Dr. Sylvie Bonvalot, France [talk about the latest data](#).

## MORE MEDICAL NEWS

- ESMO recently published the "**Clinical Practice Guidelines on bone sarcomas**". They were updated in partnership with EURACAN (European Reference Network for Rare Adult Solid Cancers) and PaedCan (European Reference Network for Paediatric Oncology). Access them [here](#).
- Do GIST patients with intermediate or high risk of recurrence benefit from 5 years imatinib post-surgery? [This study gives](#)



answers.

- Good news for US desmoid patients: **Nirogacestat** received FDA fast track designation for the treatment of adult patients with **desmoid tumours**. Read [more](#).
- **Osteosarcoma** is a challenging disease with little improvement in survival for three decades. To further improve outcomes, international collaboration is essential. That is why the **4th European Bone Sarcoma Networking Meeting in June 2017** focused on osteosarcoma. The **report** has now been published, read more [here](#).
- Time to rethink chemo doses in **high-risk, localized Ewing sarcoma**? A randomized study investigated if consolidation high-dose chemotherapy improved the survival in patients with localized Ewing sarcoma at a high risk for relapse. Read [more](#).
- **Age matters** – this holds true for **sarcomas**, found a recent UK study, initiated and supported by **Sarcoma UK**. Find out [more](#).
- Even though **GIST** generally respond well to treatment, drug resistance can develop over time. However, scientific understanding of this disease is growing and enables the development of targeted agents. Read more in [“Translational insights into gastrointestinal stromal tumor and current clinical advances”](#).



## FOUNDATION OF “PAEDIATRIC AND SDH- DEFICIENT GIST CONSORTIUM”

**Paediatric, adolescent, wild type, syndromic GIST (PAWS-GIST)** generally affect children and young adults and are rare. Treatments available for GIST are often less effective for PAWS-GIST patients. To change this situation and to drive research forward, **GIST SUPPORT UK** as well as the **LIFE RAFT GROUP (LRG)** unites with world experts as founding members of the **“International Paediatric and SDH-deficient GIST Consortium”**. Read [more](#).



## DTRF ANNUAL PATIENT MEETING 2018



THE DESMOID TUMOR  
RESEARCH FOUNDATION

**The Desmoid Tumor Research Foundation (DTRF)** Patient Annual Meeting and DTRF International Research Workshop took place on the weekend 22nd and 23rd of September 2018.

It was a fantastic meeting with medical experts, patient advocates and patients from all over the world. The patient meeting this year was mainly focused on connecting with other desmoid patients, participating in informative lectures and roundtable discussion followed by a race through Philadelphia on the next day to found money for further research projects. The second day was focused on research updates, in human genetics,

drug development and related fields presented by the international medical experts community.

Prof Peter Hohenberger (Germany) presented the paper “[The management of desmoid tumors: A joint global evidence-based consensus approach for adult and pediatric patients](#)” This paper was a global initiative from experts with expertise in adult and pediatric desmoid patients and patients and patient advocates. This initiative was supported by the DTRF, sos-desmoid Germany, and SPAEN.

Thanks to Jeanne Whiting, President and Co- Founder, DTRF and Marlene Portnoy, Executive Director and Co-Founder, DTRF for this great meeting and the fruitful collaboration during the last years!



## WORRYING DELAY IN BONE CANCER PATIENTS RECEIVING THEIR DIAGNOSIS

The [Bone Cancer Research Trust](#) (BCRT) in the UK asked 394 primary bone cancer patients about their diagnosis – and received worrying results. [Read more](#) about the **largest BCRT survey about diagnosis of bone sarcomas in the UK**.

## 11TH ONCO RUN IN POLAND



In September 2018, the „**11th Oncorun / Onkobieg**” took place in **Warsaw, Poland**. 2.200 participants expressed their solidarity with oncological patients and their families and did a total of 15.350 laps (23.025 km) around the Oncology Center - Institute in Warsaw. This translated into PLN 92.000, which will be used to support patients in need.

Organizer of the “Onkobieg” is the Polish Sarcoma organization “[Stow. Pomocy Chorym Na Miesaki SARCOMA](#)”. Get an impression of the 11th Oncorun in Poland [here](#).



## NEW DESMOID GROUP FOUNDED IN ITALY

A new desmoid group was recently founded in Italy: **The Desmoid Foundation**



**Alessandro Gronchi**  
@alegronchi

Following

Founding the @Demoid Foundation, the Italian association of desmoid patients. A great start at the National Cancer Institute in Milan, thanks to 3 brilliant young #desmoid patients. We're all excited to help!



### FOUNDATION OF THE “AUSTRALIA AND NEW ZEALAND SARCOMA ASSOCIATION LIMITED” (ANZSA)

The **Australian Sarcoma Group (ASG)** and the **Australasian Sarcoma Study Group (ASSG)** have decided to merge and from the new “**Australia and New Zealand Sarcoma Association Limited**” (**ANZSA**). ANZSA will remain a non-profit charitable organisation, with the purpose of improving the outcomes of patients affected by sarcoma and related tumours through research, education and advocacy. [Read more.](#)



### WHAT IS THE ROLE OF PATIENT ADVOCATES TODAY?



The role of patient advocates (PAs) has evolved over time: It has expanded ranging from direct support to patients and families to research and public influence. Especially in rare cancers, patients face additional difficulties. Therefore, PAs are assuming an **increasingly more active role as partners of all other stakeholders** including healthcare professionals, academics, companies, regulators, and politicians. Read about the views of **Ornella Gonzato** and **Alessandro Gronchi** [here](#).



### 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](http://www.ctos.org)



SPAEN CONFERENCE 2019  
SAVE THE DATE!

Athens/Greece  
1-3 February 2019



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CANCERS  
EUROPE  
E

EUROPEAN  
MUSCULO-SKELETAL  
ONCOLOGY SOCIETY

**SPAEN Annual Conference 2019**, February 1-3, 2019, Athens, Greece  
Click [here](#) to see our preliminary programme and to register!

**RCE-ESMO-ESO Training Course for Rare Cancer Patient Advocates 2018**, December 1-3, 2018, Milan, Italy

COURSE: **A multidisciplinary approach to the diagnosis of bone tumours**,  
March 25-27, 2019, Leiden, The Netherlands

**European Musculo-Skeletal Oncology Society (EMSOS)**,  
May 15-17, 2019, Florence, Italy:  
<https://www.emsos2019.eu/node/18>



## ABOUT SPAEN

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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