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Sarcoma Patients EuroNet - Newsletter No. 4/2018

Dear SPAEN members and friends,

Exciting times! In September, we will kick off our **“SPAEN Advocacy Campus”!**

The “SPAEN Advocacy Campus” stands for training, education and mutual exchange of patient group leaders and patient experts about disease-specific topics, capacity and personal skills building and sharing best practices.

In a first step, we will offer a series of webinars for patient advocates and patient experts, hosted by renowned international experts – see below for details. More will come, stay tuned!

Warmly,
The SPAEN Board of Directors & Team



SPAEN WEBINARS



NEW: We are starting our series of webinars for sarcoma GIST and desmoid patient advocates and patients! Our first webinar will be held by Rick Haas, MD, PhD, radiation-oncologist of the Netherlands Cancer Institute, The Netherlands. He will be talking about **“The role of radiotherapy in sarcomas & recent developments”**.

Save the date now: September 19, 2018, 6 pm CET

No registration necessary, just join in!

More info [here](#).



Last year, we announced the “SPAEN Advocacy in Action Award” for the first time and were amazed to receive such high-quality, outstanding and interesting submissions. Reason enough for us to continue to make some noise about the projects and initiatives that are being implemented each day, each month or each year in various countries. We want to again celebrate and honour outstanding practices, projects, initiatives or campaigns and the creators working behind these activities.

We therefore invite you to participate in the **“SPAEN Advocacy in Action Award 2018”!**

Deadline for submissions: November 1, 2018.

Award Ceremony: During the 9th SPAEN Annual Conference, February 1-3, 2019 in Athens/Greece. More info [here](#)



EMA PUBLISHES DATA ON ALL AUTHORISED MEDICINES



The European Medicines Agency now provides a public database with all medicines authorised in the European Economic Area (EU plus Norway, Iceland, Liechtenstein). Up until now, the EMA had already published the data of all medicines approved by EMA via the centralized procedure. The new database now also lists those medicines approved in the decentralized procedure by the Member State authorities.

In this database, patients can also find contact details and additional information about pharmacovigilance enquiries, such as reporting adverse events. Read [more](#).

STUDY REGISTRY: CHECK FOR CURRENTLY RECRUITING STUDIES



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 internationally.

For GIST, there are some novel drugs currently being tested in different clinical trials: In the [CrenoGIST study](#) (Crenolanib), the [Invictus study](#) (DCC-2618) and the [Voyager Study](#) (Avapritinib). Especially the latter two are opening up more and more sites – please check our website and the [clinicaltrials.gov](#) site for current information (trial-specific links are on our website)!

TARGETED DRUG THERAPY TRIAL NOW OPEN FOR PATIENTS WITH ADVANCED OR METASTATIC CHORDOMAS

A new **phase 2 clinical trial** testing the effectiveness of a targeted drug therapy called **afatinib** is now open to chordoma patients 18 years or older with recurrent, locally advanced, or metastatic tumors, informs the Chordoma Foundation. More information about the trial can be found [here](#).

THE ROLE OF ISOLATED LIMB PERFUSION (ILP)

Induction chemotherapy by ILP is an effective strategy to facilitate limb-conserving surgery in locally advanced extremity sarcoma. Researchers have now compared regional chemotherapy by ILP prior to surgery with surgery and post-operative radiotherapy. They have found that **ILP prior to surgery is not inferior to standard management**. Read [more](#).

STUDY RESULTS: NANOPARTICLE THERAPY PROMISING IN SOFT TISSUE SARCOMA

Radiation therapy is a major pillar in sarcoma management. However, its efficacy is limited by toxicity on healthy tissue. Outcomes in terms of tumour shrinkage are unsatisfying.

Nanoparticle therapy might change that as it has **the potential to improve the outcomes of radiotherapy**. NBTXR3 is currently tested in clinical trials – it is applied together with radiation therapy and physically destroys cancer cells when activated by radiation therapy. **Data from a phase II/III trial** have now been published and seem very promising. Read [more](#).

The company's own press release can be accessed [here](#).

OSTEOSARCOMA STUDY SHOWS POSITIVE RESULTS OF REGORAFENIB

The Sarcoma Alliance for Research Through Collaboration (SARC) recently reported positive results of their osteosarcoma trial of regorafenib. The goal of **improving progression-free survival for patients** receiving regorafenib on this study has been met. Read the press release [here](#).



THE LIFE RAFT GROUP: LIFE FEST 2018



Life Fest, organized by the US group The Life Raft Group (LRG), is a unique event where hundreds of patients and caregivers come together for a weekend to interact with each other and the medical and scientific communities that serve them. **Life Fest 2018 was held in Miami, Florida, July 13-15th - read more [here](#)**.

2018 DTRF PATIENT MEETING, SEPTEMBER 22, 2018



The Desmoid Tumor Research Foundation (DTRF) will be holding their annual Patient Meeting again: Join them for a weekend of connecting and learning! This year's Patient Meeting will be held on Saturday, September 22nd. Registration will begin at 12pm, and the meeting will end around 5pm with mingling until 6pm. Running for Answers will take place the following day, on Sunday, September 23rd. More information [here](#).

PATIENT DAY FOR SARCOMA AND GIST PATIENTS IN ESSEN, GERMANY

The German organization "[Das Lebenshaus](#)" organizes together with Essen University Hospital a patient day dedicated to soft tissue sarcoma, bone sarcoma and GIST patients.

It will take place August 31st in Essen, Germany. Further information and registration details can be found [here](#).



FINLAND: VILLE CYCLES FOR SARCOMA

In Finland, 250-400 people are diagnosed with sarcoma every year. There are no official sarcoma centers. Yet, **sarcoma patients desperately need specialized care** (no matter where they live!).



Ville Laakso is one of those patients. The father of two boys was diagnosed 10 years ago with an ultra-rare type of cancer and even sarcoma: Mesenchymal chondrosarcoma. This year, he's living one of his long-term dreams: to **cycle a three days stage race through three Finnish cities with university hospitals**: Turku to Helsinki to Tampere and back - 600 km from **September 7 to 9, 2018**.

But not just for his own pleasure, but to raise awareness for sarcoma - especially with doctors. With the **long-term aim to optimize, broaden and professionalize sarcoma care in Finland** - an aim certainly worth supporting! Read about Ville's story and plans [here](#).

ELFSTEDENTOCHT - FUNDING FOR CANCER RESEARCH PROJECTS INCLUDING OSTEOSARCOMA IN THE NETHERLANDS



The Elfstedentocht (Eleven Cities Tour) is the biggest ice-skating tour in the world. The waterways between eleven Frisian cities form the 200 kilometer track of the Eleven Cities Tour. That's why this sensational ice-skating event can only take place during severe winters. This summer **Maarten van der Weijden will attempt to swim the 200 km tour non-stop in three days (18, 19 and 20 August)**. Maarten is a survivor of acute leukemia. After he recovered he won the gold medal 10 km open water at the 2008 Olympic Games in Beijing. His aim is to raise funding for cancer research. Eleven projects, one for each city, have been selected that will be featured during this event. **One of these projects is on sarcoma. This research project is investigating the possibilities to apply immunotherapy to osteosarcoma**. It is wonderful that Maarten is making this effort, which will receive a lot of media attention, to raise money for sarcoma research. It is also an excellent opportunity to raise awareness for sarcoma in general and for the need for more research on sarcoma in particular.

Follow the event on:

- 11stedenzwemtocht.nl
- facebook.com/MvdWFoundation/
- Twitter: [@mvdwfoundation](https://twitter.com/mvdwfoundation)



NCCN PATIENT GUIDELINES FOR SOFT TISSUE SARCOMA

The US-American "National Comprehensive Cancer Network" (NCCN) just recently published [Guidelines for Patients](#) about Soft Tissue Sarcomas.



PREEMINENT CANCER BIOLOGIST BRIAN DRUKER, M.D., RECEIVES INTERNATIONAL SCIENCE AWARD

Brian Druker, the “father” of Imatinib, was awarded the 2018 Tang Prize in Biopharmaceutical Science. Druker’s research proved it was possible to shut down cancer cell growth without harming healthy ones – which made diseases such as GIST manageable. Read more [here](#).

Photo: Wikipedia



EURACAN NEWSLETTER



The latest edition of the EURACAN newsletter is available [here](#).

EURACAN stands for the **European Reference Network (ERN) for Rare Adult Cancers**. More information is available [here](#).



SOFT TISSUE SARCOMA CONFERENCE IN VELLORE, INDIA

The Christian Medical College, located in Vellore, India, celebrated the centenary of medical education, which began in 1918 – with the **STSCON 2018**, a conference about Soft Tissue Sarcomas held in June 2018. It aims to improve current knowledge, by creating a platform to exchange ideas with global experts in the field. The international faculty also held renown sarcoma experts such as Dr. Paolo Dei Tos and Dr. Alessandro Gronchi, Italy, Dr. Aisha Miah, UK, Dr. Shreyaskumar Patel, USA and Dr. T. Agathian, Singapore. More info [here](#).

OSTEOSARCOMA INSTITUTE

The Osteosarcoma Institute (OSI) was established in November 2017 to develop a comprehensive, rational strategy to improve the life expectancy of osteosarcoma patients.

The institute has now announced two **Requests for Proposals (RFP)**, one for a clinical trial and the other to support a preclinical/translational research project. Find out more [here](#).



WHERE NEXT FOR PATIENT INVOLVEMENT IN RESEARCH?

The editorial [“Patients’ roles and rights in research”](#) in BMJ 2018 states that **“Full partnership with patients is essential to any modern research enterprise”**. This inspired SPAEN Honorary President Roger Wilson to add some of his own thoughts. Read [here](#).

WECAN SURVEY



The contribution of patients and patient experts provides tangible value to stakeholders and society. **“Should this work be fairly compensated?” asks the WeCan Network.**

If you are a patient advocate: Now is the time to answer this question and **take part in the WeCan Survey**. More information [here](#).

About WECAN: WECAN is an informal network of leaders of cancer patient umbrella organisations active in Europe. Their mission is to strengthen patient advocacy in Europe and to improve outcomes for all cancer patients. For more information: <http://www.wecanadvocate.eu/> and [WECAN on Facebook](#).

ACCELERATE: INCLUSION OF ADOLESCENTS IN ADULT PHASE-I TO III TRIALS

“There have been huge advances in cancer drug development. But not for children. They are not a priority.”

Earlier this year, we [reported](#) about the multi-stakeholder platform ACCELERATE, which proposes the inclusion of adolescents in adult phase-I to III trials of cancer drugs targeting a relevant disease or mechanism of action, without requiring preceding specific paediatric trials. This is especially important to us as bone sarcomas very often occur in children, adolescents and adults.

The parent-led movement [Unite2Cure](#) has now released a video about this topic – go watch [here](#).

Additionally, the publication “Joint adolescent–adult early phase clinical trials to improve access to new drugs for adolescents with cancer: proposals from the multi-stakeholder platform—ACCELERATE” has been published and is fully accessible [here](#).



New Horizons GIST 2018, September 5-7, 2018, Vienna, Austria



ECCO 2018, September 7-9, 2018, Vienna, Austria:

<https://www.eccosummit.eu/>



GEIS XVth International Symposium, October 4-6, 2018, Seville, Spain

<http://www.grupogeis.org/eventos/symposium-2018/>

ESSO: Congress of the European Society of Surgical Oncology

October 10-12, 2018 in Budapest, Hungary

<https://www.essoweb.org/events/esso38/>



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:

<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

SPAEN CONFERENCE 2019
SAVE THE DATE!

Athens/Greece
1-3 February 2019



SPAEN Annual Conference 2019, February 1-3, 2019, Athens, Greece



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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