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Sarcoma Patients EuroNet Newsletter No. 2/2017

Dear SPAEN members and friends,

As the leaves are turning red already, we are in the middle of preparing the next SPAEN Annual Conference and are more than happy to share the good news with you: The European Society of Medical Oncology (ESMO) and SPAEN have decided to combine their meetings. For the first time, the SPAEN Annual Conference and the ESMO Sarcoma and [GIST](#) meeting will be held in conjunction at the Marriot Hotel in Milan, Italy in February 2018.

The SPAEN Annual Conference will take place on February 3-4, the ESMO Sarcoma & [GIST](#) meeting from February 5-8, 2018 – please SAVE THE DATE!

For more information, please check our [website](#). We will contact you as soon as the programme becomes available and the conference is open for registration.

Stay tuned and check our website, Facebook page and Twitter channels for updates.

Kind regards,
the SPAEN Board of Directors & team




ASCO 2017
REPORT



The Annual Meeting of the American Society of Clinical Oncology (ASCO) is one of the most important meetings of healthcare professionals in the world.

We are therefore delighted to provide you with a comprehensive report about the **ASCO 2017 medical highlights in [GIST](#) and Sarcomas from Dr Axel Le Cesne**, Gustave Roussy Institute, Villejuif, France, translated into English by Estelle Lecoite-Artzner, France and edited by Roger Wilson, UK and Markus Wartenberg, Germany. Read more [here](#).




**SPAEN ANNUAL
CONFERENCE REPORT,
WARSAW, POLAND 2016**

In September 2016, the community of patient advocates for sarcomas, [GIST](#) and desmoids came together for another successful SPAEN Annual Conference, with Poland being a welcoming host country.

The three conference days were full of learning about medical topics, updates from research, capacity building as well as about sharing experience. For the sarcoma patient community, the SPAEN conference is always a valuable platform with an opportunity to learn about advances and challenges in the treatment of sarcomas, [GIST](#) and desmoids and to share experience and best practice. The 2016 conference was again a balanced symbiosis of medical content, advocacy topics and capacity building sessions.

Read more about what was discussed and shared in our [conference report](#).



**BOOK VOICES OF
COURAGE AND HOPE –
CALL TO ACTION**

Cancer patients know and have experienced that it can be not only helpful, but truly empowering to be part of patient community such as SPAEN. We would like to spread this inspiring and motivating feeling among other patients out there.

We plan to create and publish a book of individual patient stories from different countries around the world – together with you! **We ask you to share your story with us - become part of “The Voices of Courage and Hope”**. Find out more on our [website](#)!



**ESMO ANNUAL MEETING,
SEPTEMBER 8-12, 2017,
MADRID, SPAIN**

One of the most important European meetings for healthcare professionals in oncology was held from September 8-12, 2017 in Madrid, Spain. A lot of important information has been presented, including news about [GIST](#):

[DCC-2618](#) is a novel treatment option in metastatic [GIST](#) and has shown encouraging results in a dose-escalating study.

Furthermore, an [EORTC study](#) showed a trend towards prolonged relapse-free survival and overall survival (not significant) in patients with high-risk [GIST](#) treated with imatinib for 3 years. This is consistent with the findings of earlier studies. Please click on the links for further information provided by ESMO.

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](#) for some of the clinical trials available worldwide and find some highlights here:

[CABO-GIST](#): Cabozantinib might be a new option for patients with metastatic [GIST](#) who progressed during [neoadjuvant](#), [adjuvant](#) or [palliative](#) therapy with imatinib and sunitinib. The CABO-[GIST](#) is a Phase II study assessing the safety and efficacy of Cabozantinib in [GIST](#).

[Cabozantinib in HGUs](#): Cabozantinib belongs to a family of drugs that have effects on tumour growth, blood supply, invasion and spread. This trial tries to find out whether taking cabozantinib after treatment with surgery and chemotherapy is effective and safe for patients who responded or had stable disease after their chemotherapy.

[The D842V mutation in GIST](#) is known to be insensitive to standard treatment with Imatinib. Currently, two studies are open and recruiting patients with that specific mutation: A phase I study with BLU-285 and a phase III study with [Crenolanib](#).



SIDEEQ

Side effects are practically inevitable, but can affect a patient's quality of life and ability to maintain their drug regimen immensely. Therefore, the Life Raft Group, a patient group with a focus on [XXGIST](#), set up a free tool to help patients gain valuable insights into symptoms and side effects management: [SideEQ](#).



Only this year, the [National Leiomyosarcoma Foundation](#) announced a collaboration with the [Life Raft Group](#) on this specific project, allowing also LMS patients to profit from this tool. For more information, please check out the website: <https://www.mysideeq.org/>

Both organisations are non-profit organizations based in the USA and full members of Sarcoma Patients EuroNet (SPAEN).

LARGEST ONCORUN IN POLAND: THE "ONKOBIEG"



On September 3, the **biggest run for oncological patients in Poland took place for the 10th time**. It is a charity run to show support and motivate those who suffer from cancer. The raised money goes to patient support – both financial support such as purchasing medicines, rehabilitation or [XXpalliative](#) care, but also for direct contact to patients.

Approximately 2.000 people came together and ran 16.447 km (!) to raise money, to support cancer patients and to celebrate life. More information:

<http://www.onkobieg.pl/>

GIST AWARENESS DAY CELEBRATION, FRIENDS OF MAX

On Saturday the 8th July 2017, The Max Foundation arranged a grand celebration of [GIST](#) Awareness Day (GAD) for its Support Group Arm Friends of Max at the TATA Memorial Hospital, Mumbai, India.

GAD is an annual event in July celebrating the survivors of the rare cancer [GIST](#). This was the fourth year of celebrations. Find out more [here](#).

UNITED – THE NEW MAGAZINE OF THE BONE CANCER RESEARCH TRUST

Do you want to learn more about primary bone cancer? Then have a look at the **new magazine of the [Bone Cancer Research Trust](#)** that was just released end of July for the first time:

<https://issuu.com/bonecancerresearchtrust/docs/united>.

The BCRT is a non-profit organization in the UK providing information on all kinds of bone cancers and a

full member of SPAEN.

MEMBER ACTIVITIES

Please find the member activities (selection) also on our [website](#).

Do you have a project or information you would like to share? Please contact us on info@sarcoma-patients.eu



INTERESTED IN EWING SARCOMA?

The [EURO EWING Consortium](#) (EEC) is running a call for applications for travel scholarships 2017/2018 open to researchers and health professionals working in Europe. All information can be found [here](#).

Funding was donated by the [Associazione Paola per i tumori muscolo-scheletrici](#) - a special thanks to former SPAEN Board member Ornella Gonzato and EEC patient expert, who initiated the donation.

LATEST EUROSARC NEWSLETTER AVAILABLE NOW

The new **EUROSARC** newsletter has recently been published – please find it [here](#).

More info about the EU project EUROSARC is available [here](#) or at <http://eurosarc.eu/>



NEW HORIZONS GIST 2017: OCTOBER 1-3, 2017

NEW HORIZONS [GIST](#) is a great event where patients from the Global [GIST](#) Patient Community come together, can interact with top [GIST](#) experts, have access to state-of-the-art medical and scientific information and can exchange best practice in patient advocacy among each other.

The next NEW HORIZONS [GIST](#) conference will take place on October 1-3, 2017 in New Jersey, USA. For more information, please contact Sara Rothschild on srothschild@liferaftgroup.org

CTOS 2017

The Annual Meeting of the [Connective Tissue](#) Oncology Society will be held November 8-11, 2017 at on the island of Maui in Hawaii, USA: www.ctos.org

RARECANCERS MEETING AND TRAINING COURSE

[2nd ESO-ESMO-RCE Clinical Update on Rare Adult Solid Cancers](#) will be held December 2-4, 2017 in Milan, Italy.

This year we are amid the process of creation of the new European Reference Networks (ERN) on rare diseases, including rare adult solid cancers, with the ERN named EURACAN. Many speakers and moderators will thus come from EURACAN and definitely will be happy to meet Oncologists working within it or in collaboration with it.



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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