



SPAEN – NEWS

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

Sarcoma Patients EuroNet Newsletter No. 1/2017

**Dear SPAEN members
and friends,**

It's already a couple of months into the new year and so much has happened. One of the most important projects this year has been the launch of our new International Sarcoma Online Platform – providing a lot of background information about Soft Tissue and Bone Sarcoma, **GIST** and Desmoids. Most of it is already available in different languages apart from English, such as Italian, French, German, Spanish and Hebrew. A special thanks to our national groups who took on the translations very enthusiastically – it couldn't be done without you! This is another proof for what we can achieve when we combine our strengths – let's keep on, because ***“Together we can make a difference to those affected by sarcomas”!***



CHANGE OF STATUTES

Though this sounds very formal, it really is quite practical: During our 7th Annual Conference in Warsaw, Poland in September 2016, we decided to change three aspects of our statutes:

SPAEN is now international: Having evolved from a European to an international network, we are more than happy to welcome “old friends”, formerly associate members as well as new allies from all over the world among us. Please take a look at our member list – and if you haven't updated your profile yet, please do so!

Three Forms Of Memberships: Full members (Patient Advocacy Groups, voting rights in the AGM), Corporate members and supporters (no voting right) and Appointed Board Members: The elected board of directors has the right to appoint up to 7 persons to support the elected board in their tasks.

The Board has appointed two observers to the Board – Jesica Garcia, Spain/UK and Ferdinand Mwangura, Kenya – as well as Professor Bernd Kasper, medical oncologist and secretary of the EORTC Soft Tissue and Bone Sarcoma Group. We'd like to warmly welcome all new full members

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MICHAEL SAYERS



It is with great sadness that we announce the passing of our Board Member Michael Sayers.

He was elected on the SPAEN Board in 2014 and has since contributed vitally in achieving SPAEN's goal "Together we can make a difference for those affected by Sarcomas".

We are very grateful for his valuable work – Michael, you will dearly be missed! R.I.P.

NEW MEMBERS IN OUR SCIENTIFIC BOARD

Collaborating closely with the experts has always been one of the principles of our work. We are therefore very happy to welcome three new members among our Medical Advisory Board:

1. Dr. Robin Jones, Medical Oncologist, The Royal Marsden, London, UK
2. Prof. Bernd Kasper, Medical Oncologist, University Hospital of Mannheim, Germany,
3. Craig Gerrand, Orthopaedic Surgeon, Freeman Hospital, Newcastle upon Tyne, UK

Find out more about our [SPAEN Scientific Board](#).

SPAEN'S SARCOMA POLICY PAPER



Misdiagnosis, inappropriate and non-expert treatment are unfortunately common in sarcomas. Our Honorary President Roger Wilson and SPAEN's co-chairs Estelle Lecointe-Artzner and Markus Wartenberg therefore developed a policy paper about what we as patient advocates expect sarcoma treatment to look like, how service structures should develop to respond to patient needs, and how national and international referral practice should evolve.

The "Sarcoma Patient Pathway Analysis and Recommendations for Service Development" was awarded "Best Abstract" by the scientific committee of the European CanCer Organisation (ECCO) and was presented during the annual ECCO congress.

Read the SPAEN sarcoma policy paper [here](#)
And the press release [here](#)

We've also contributed to creating a policy paper focusing on the situation of sarcoma patients in various countries. Please find this paper [here](#) – available in French, Spanish, German, English and Italian.

EORTC QOL CONFERENCE



This 2-day conference covered a broad range of topics in Health-Related Quality of Life (HRQL), patient reported outcomes (PRO), Symptom

This 2-day conference covered a broad range of topics in Health-Related Quality of Life (HRQOL), patient reported outcomes (PRO), Symptom Research and Cancer Clinical Trials and policies. It is a platform to discuss recent developments of tools as well as other systems for use in clinical trials as well as international developments and research guidelines. Among the 30 senior PRO international leaders was our Honorary President Roger Wilson as speaker, talking about "Pathway to Patient Benefit" and "Survival -diagnosis or lifestyle".

Find our more [here](#).



OLARATUMAB APPROVED IN ADVANCES STS

End of last year, Olaratumab received the approval of the European Commission for front-line therapy in combination with doxorubicin in advanced soft tissue sarcoma. Olaratumab (trade name: Latruvo) is the first approved monoclonal antibody in this disease.

Read [more](#)



EURO EWING CONSORTIUM



The EURO EWING Consortium (EEC) is a collaborative project supported by the European Union, that brings together the most active clinicians and scientists in Europe dedicated to improving survival from Ewing sarcoma.

Through collaborative working, the EEC will provide Ewing Sarcoma patients with greater access to clinical trials, allow efficient acquisition of knowledge and deliver clinically meaningful results within 5 years, thereby contributing to improved survival from Ewing Sarcoma.

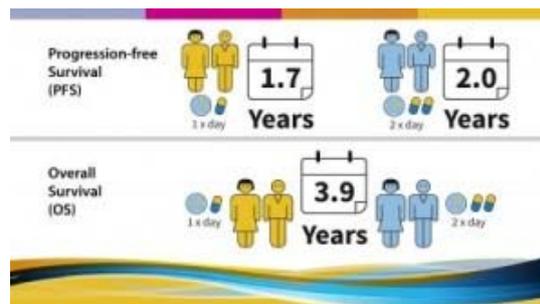
The EEC is currently running two studies that are still recruiting in several countries across Europe: [rEECur](#) and [Euro Ewing 2012](#).

See the [EEC Website](#) for more information.



400 MG VS. 800 MG PER DAY IMATINIB (GLIVEC) IN GIST?

The 62005 trial looked at the question whether the higher dose of imatinib (800 mg/day) was superior to the standard dose (400 mg/day) in patients with gastrointestinal stromal tumours. Recently, the ten year data were published.



Want to know more? Click [here](#).





PATIENTENPLATFORM SARCOMEN

The Dutch organizations for **GIST** and Sarcoma have decided to merge their groups in one and now offer information and support for **GIST** and all other types of sarcoma patients in the Netherlands and Dutch speaking part of Belgium. Find the profile of the Patientenplatform Sarcomen in the Netherlands [here](#).

ONE PICTURE SAYS IT ALL: THE MAX FOUNDATION AND FRIENDS OF MAX, INDIA



The Max Foundation together with The Friends of Max held the Mumbai City Chapter Meet at the Tata Memorial Hospital on Sunday 14th May with over 230 participants, the physicians Dr Manju Sengar and Dr Suresh Advani and the Volunteers and the Max Foundation team, that made it all possible. Find Friends of Max [here](#).

ENGLISH EAST AFRICA INTERNATIONAL PATIENT ADVOCACY GROUP SUMMIT HELD BY HENZO KENYA



On May 20, 2017, the first ever EEA (English East Africa) International PAG (Patient Advocacy Group) Summit was held in Nairobi, Kenya. It was attended by over 160 CML, **GIST** and sarcoma patients from Kenya, Sudan and Ethiopia.

The aim of the summit was to bring together patient leaders from Eastern Africa to share and learn from each other, but also to address the challenges the group and the region is facing. A working group was formed responsible for spearheading communication and activities across the region.

Please find more information about Henzo Kenya [here](#).



BRITISH SARCOMA GROUP ANNUAL MEETING 2017

The latest advances in treating patients with soft tissue sarcomas (STS) were under discussion during the British Sarcoma Group's 13th Annual Conference in Bristol. The meeting highlights are available [here](#).

BRITISH SOFT TISSUE SARCOMA AND BONE SARCOMA GUIDELINES UPDATED

Guidelines on the Management of Soft Tissue Sarcoma and for Bone Sarcoma have recently been updated and can be downloaded [here](#).

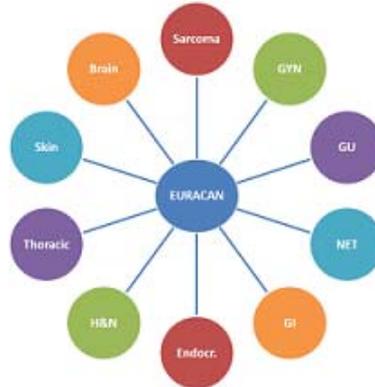


EUROPEAN REFERENCE

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EUROPEAN REFERENCE NETWORKS STARTED

The first 24 ERNs were launched in May 2017, involving more than 900 highly-specialised healthcare units from over 300 hospitals in 26 Member States. More than 300 rare cancers have been identified. ERN EURACAN covers all rare adult solid tumour cancers including sarcomas, grouping them into 10 domains.



EURACAN

European network for
Rare adult solid Cancer

The management of rare cancers poses significant diagnostic challenges, sometimes with major consequences for patients' quality of life and outcome. Inappropriate management of these patients may also result in an increased risk of relapse, and risk of death.

ERN EURACAN is sharing best practice tools and establishing reference centres for rare cancers. It is also establishing regularly updated diagnostic and therapeutic clinical practice guidelines. The network aims to reach all EU countries within 5 years and develop a referral system to ensure at least 75 % of patients are treated in a EURACAN centre. It seeks to improve patient survival, produce communication tools in all languages for patients and physicians, and develop multinational databases and tumour banks.

The ERN builds on pre-existing clinical and research networks that have successfully conducted clinical trials through the European Organisation for Research and Treatment of Cancer (EORTC), and established guidelines through EORTC and the European Society for Medical Oncology (ESMO). It also benefits from the work of networks formed by the European Neuroendocrine Tumour Society (ENETS) and Connective Tissues Cancer Network (Conticanet), as well as several EU research projects.

SPAEN is actively involved in the EURACAN network.



ASCO ANNUAL MEETING 2017

ASCO Annual Meeting 2017

The Annual Meeting brings together oncology professionals from around the world to discuss state-of-the-art treatment modalities, new therapies, and ongoing controversies in the field. For SPAEN it is an important platform to foster international collaboration. We will share a report about the latest news in **GIST** and **Sarcomas**.

ESMO 2017 MADRID

ESMO Congress 2017, Madrid/Spain
8 -12 September 2017

Since ESMO 2016, the ESMO Patient Advocacy Track has been fully integrated into the congress programme, enabling patient advocates to attend the scientific sessions that are relevant to them as well as the patient advocacy sessions.

Programme of the [ESMO Patient Advocacy Track](#)



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.

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For Those Affected By Sarcomas!**



CONTACT

SPAEN CONTACT

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