

View it online if you can't see pictures



# SPAEN – NEWS

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

Sarcoma Patients EuroNet Newsletter No. 2/2018

**Dear SPAEN members and friends,**

the last weeks have been filled with activity – we held our SPAEN Annual Conference for the first time in conjunction with the expert meeting “ESMO Sarcoma & [GIST](#) symposium” in February in Milan, Italy. We even had the chance to deliver some of our most pressing topics to the experts directly during our SPAEN Roundtable as part of the official ESMO programme.

But we also took care of the future of SPAEN: New board members have been elected and appointed, experienced board members have been re-elected (read more below).

We are very excited and look forward to working in a strong team with expertise in different areas, many years of experience in advocacy and a lot of fresh ideas.

Kind regards,  
the SPAEN Board of Directors & team



## **R.I.P. FERDINAND MWANGURA**



It's with great sadness that we learned of the passing of Ferdinand Mwangura, our friend and SPAEN Board Member on 28th February 2018. Ferdinand was loved and respected in our community. He was restless in the fight against cancer and in his work for [GIST](#) and CML patients in his home country Kenya. Ferdinand, we will deeply miss you, but your passion and energy will stay with us to drive systematic change.

R.I.P. Ferdinand.

If you would like to support Ferdinand's family, please have a look at the [initiative](#) the CML community took.

## **THE SPAEN BOARD OF DIRECTORS – EXPERTISE, EXPERIENCE AND FRESH**

The “SPAEN Board of Directors” is a voluntary body of currently seven elected members. This year, the terms of Estelle Lecointe-Artzner, Markus Wartenberg, Kai Pilgermann and Christina Baumgarten ended. All of them

## IDEAS



were unanimously re-elected. Estelle and Markus have been confirmed as co-chairs of the board and are happy to continue the task.

The board of directors also gladly welcomes two newly elected/appointed members to the board: Annika Laakso from Finland and Sami Sandakly from France.

We are looking forward to continuing our work with new and “old” members of the board, because “Together we can make a difference for those affected by sarcomas”. See our current [Board of Directors](#).

## SPAEN ANNUAL CONFERENCE 2018

In the last years a growing number of participants demonstrated the increasing interest in the sarcoma field. This year’s conference attracted around 80 participants from all over the world: patient advocates, leading sarcoma experts and representatives of the healthcare industry.



It was the first truly international meeting after the decision to make SPAEN an international organisation in 2016 and held for the first time within the framework of the ESMO Sarcoma & [GIST](#) Symposium 2018.

[Get an impression here](#).

And hear Roger discuss with Professor Jean-Yves Blay about the [highlights of the SPAEN roundtable](#) held in cooperation with the experts during the official ESMO programme.



## ESMO GIST & SARCOMA SYMPOSIUM



Want to know what has been discussed during the ESMO conference, check out the [ESMO youtube channel](#).

## PATIENT LED PROMS MUST TAKE CENTRE STAGE IN CANCER RESEARCH



„After 15 years as an involved patient in cancer research I started looking around and I found I was asking myself, where is the next leap in real patient benefit going to come from?

Evidence based practice is asking researchers to find the true value of new treatments. I came to the conclusion that quality of life assessment and patient reported outcome measures (PROMs) which capture subjective patient experience are where real and lasting progress can be made.”

Roger Wilson.

Read more about his views and thoughts on Quality of Life and PROMs in his latest publication in [“Research Involvement and Engagement”](#).



### **VCARE CANCER SURVIVORSHIP EVENT**



The VCare Foundation, India, celebrates Cancer Survivors' Day (CSD) in honour of those who have conquered cancer. On this day, VCare salutes their fighting spirit and the courage shown by them and their care givers in facing the disease and its treatment. Incepted in 1995 by V Care Foundation, CSD has now expanded to a full week program and this annual event is celebrated throughout India by other cancer support groups as well.

Read more about the activities of this year's CSD on VCare Foundation's [facebook page](#).



### **EURO EWING CONSORTIUM WINTER MEETING 2018**

The Euro Ewing Consortium is a EU-funded project with the aim to find new or improved treatment options for Ewing sarcoma. Within this project, two trials (rECCur and Euro Ewing 2012) are conducted in several countries and a lot of basic research in tissue samples, cell lines and for biomarkers is undertaken. SPAEN is part of the project and took part at the 2018 winter meeting took place January 17-18, 2018 in London, UK. Read more [here](#).

### **THE MAX FOUNDATION: REFLECTIONS FOLLOWING THE LOSS OF A BELOVED CANCER ADVOCATE**



The passing of our friend, advocate and colleague Ferdinand has shaken the patient community both in CML and [GIST](#). A lot of questions have been raised – Pat Garcia Gonzales, CEO and one of the founders of [The Max Foundation](#), put her thoughts into writing. This is not only a warm and loving good-bye to a person close to her and our hearts, but also a status quo of what we as patient advocates can achieve and where there are limits that need to be pushed further. Thanks, Pat, for this sad but nevertheless [inspiring blog](#).

### **THE ACCELERATE PLATFORM TO ACCELERATE INNOVATION FOR CHILDREN AND ADOLESCENTS WITH**

Bone sarcomas occur in children, adolescents and adults. However, the impressive progress recently observed in adult cancers through the introduction of new drugs has not yet been translated to adolescents between 12 and 17 years of age. The multi-stakeholder platform ACCELERATE, with representatives from academia, patient/parent advocacy groups, regulatory agencies and pharmaceutical companies, proposes the inclusion of adolescents in adult Phase-I to III trials of cancer

## CANCER



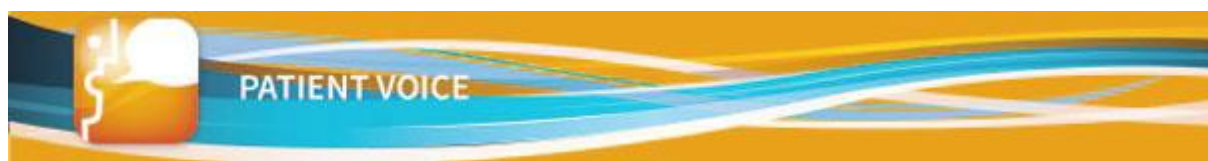
drugs targeting a relevant disease or mechanism of action, without requiring preceding specific paediatric trials. The patients are represented by the parent-led movement [Unite2Cure](#), which dedicates its work to improve treatment and access to treatment for children and young people with cancer. Please read more [here](#) and have a look at a [publication](#) available in due course.

Find out more about Unite2Cure [here](#).

## THE ANGIOSARCOMA PROJECT

This project takes a new approach to cancer research in which researchers partner directly with patients, who share their samples and clinical information in order to speed important discoveries. The project is being launched and funded by the Broad Institute of MIT and Harvard — a non-profit academic research institution with a mission to dramatically accelerate the understanding and treatment of disease — and conducted in collaboration with Dana-Farber Cancer Institute.

Sharing samples and medical records is limited to the US and Canada. However, anyone from around the world can sign up for the project to share patient reported data. Find out more [here](#).



### **The ESMO Patient Advocates Working Group: Raising the profile of advocacy**

Patient advocacy is being helped by ESMO to take its rightful place in the mainstream management of cancer. Bettina Ryll, Chair of the ESMO Patient Advocates Working Group (PAWG), says it's time to "put an end to 'them and us'" – read more about her experience in this role [here](#).



### **EORTC Patients in Research conference 2018**

This two-day course for cancer patient advocates takes place March 23, 2018 in Brussels, Belgium: <http://events.eortc.org/wpmulti/patientdays/>

### **EMSOS 2018**

The annual meeting of the European Musculo-Skeletal Oncology Society E.M.S.O.S. will be held from 9 - 11 May 2018 in NH Krasnapolsky Hotel, Dam Square, Amsterdam: <https://emsos2018.org/scientific-program/>

### **ASCO 2018**

The annual meeting of the American Society of Clinical Oncology 2018 will be held from June 5-8, 2018 in Chicago, USA:

<https://www.asco.org/2018-asco-annual-meeting#>

## 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>



### 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!**



### SPAEN CONTACT

SPAEN Secretariat  
Am Rothenanger 1b, 85521 Riemerling, Germany  
Tel: +49 89 62836807, Fax +49 89 62836808  
Email: [info@sarcoma-patients.eu](mailto:info@sarcoma-patients.eu)  
Web: [www.sarcoma-patients.eu](http://www.sarcoma-patients.eu)

SPAEN Registered Office:  
Untergasse 36 \* 61200 Wölfersheim/Germany

Follow us on [Twitter](#) and [Facebook](#)



[WWW.SARCOMA-PATIENTS.EU](http://WWW.SARCOMA-PATIENTS.EU) | [CONTACT US](#) |



Click if you want to unsubscribe