



**Sarcoma
Patients
EuroNet**

The European Perspective...

Sunday, 17th of May 2015

NEW HORIZONS GIST, Miami

Topics

- SPAEN Sarcoma Patients EuroNet e.V.
- Rare Cancers Europe RCE
- ESMO Patient Advocacy Working Group
- EUPATI - Academy

Topics

- **SPAEN Sarcoma Patients EuroNet e.V.**
- **Rare Cancers Europe RCE**
- **ESMO Patient Advocacy Working Group**
- **EUPATI - Academy**

The very 1st step – done in Paris 2006...



- 1st meeting of European PAG-leaders and representatives of CONTICANET on the 14th of December 2006 in Paris.
- As a initial basis of SPAEN other meetings in Baveno, Bad Nauheim and London followed.
- Supporter right from the start:
 - Prof. Jean Yves Blay
 - Simon Baconnier

The Founding: Bad Nauheim, April 2009



- 11 foundation members initiated the foundation of SPAEN and membership is open to patient groups working with sarcoma patients across Europe.
- SPAEN was officially founded on the 6th of April 2009 in Bad Nauheim/Germany. SPAEN is an European association – legally registered under German law.

Vision

- All Sarcoma (incl. GIST) Patients in Europe have **access**
 - to timely and correct diagnosis,
 - to information about their specific sarcoma-subtype,
 - to treatment and care in specialised centres and
 - to innovative treatment options incl. clinical trials.

Mission

**Improving the situation of Sarcoma (GIST) Patients
and their relatives in Europe!**

By

- building one strong European Sarcoma Voice,
- cooperating with all relevant European stakeholders
in an outcome-oriented way and
- strengthening this European coalition of national Sarcoma-,
GIST- and Desmoid Patient Advocacy- and Support Groups.

The Long Term POSITIONING

- A comprehensive European coalition of Sarcoma Patient Advocacy – and Support Groups, a well respected peer-to-peer partner with a strong common and influential voice.

Goal 1

- **We identify problems, challenges, access issues and unmet medical needs in sarcomas. By collaborating with leading sarcoma experts, researchers, industry and other relevant European stakeholders/ initiatives in an outcome-oriented way we find solutions and improve situations.**



Projects/Services/Tasks/Engagements

Goal 2

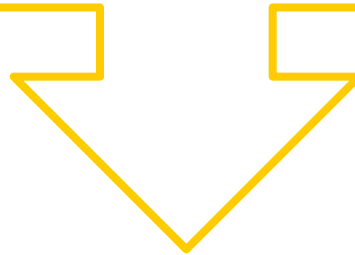
- **Sarcoma Patients need to get a timely correct diagnosis and need to be treated according to guidelines; ideally as early as possible in multi-disciplinary sarcoma expert centres. We advocate and support the implementation of these structures and the pan-European collaboration between these centres.**



Projects/Services/Tasks/Engagements

Goal 3

- **Clinical research, studies and generating evidence/data are essential for better and innovative treatment solutions. We need to be involved as early as possible in clinical trials, try to improve patients access to studies and support meaningful research – following the specific needs of rare cancer patients.**



Projects/Services/Tasks/Engagements

Goal 4

- **Sarcoma patients and their relatives need a strong “European Sarcoma Patient Voice” and strong “National Patient Support Opportunities”. That’s why we care for our members – the existing national patient organisations and the creation of new ones.**



Projects/Services/Tasks/Engagements

SPAEN Claim / Slogan...

- *The Coalition of Sarcoma (GIST) Patient Groups in Europe:
Advocacy, Collaboration and Mutual Support –
for the Benefit of Sarcoma Patients in Europe.*

The Association at a glance

- Type: European umbrella org. = foundation
- Founded: April 2009 (under German law)
- Registered Office: Wölfersheim / Germany
- Administration Office: Munich / Germany
- 26 Full Members
- 6 Associate Members
- 14 leading European Medical Sarcoma Experts
Medical Advisory Board
- 6 Sustaining Partnerships
Bayer, Merck, Novartis (GSK), Pfizer, PharmaMar, Takeda

The Board of Directors

- Co-Chairs Estelle Lecointe – FR
 Markus Wartenberg – DE
- Secretary Lindsey Bannister – UK
- Financial Director Kai Pilgermann – DE
- Expert Desmoids Christina Baumgarten – DE
- Expert GIST Michael Sayers – UK
- Expert Bone Cancer Ornella Gonzato – IT

- Advisor to the Board Roger Wilson – UK
- Medical Advisory Board
- Project Manager Michaela Geissler

Some Important Activities / Projects

Involvement
in Clinical Research
as early as possible

Involvement
in 2 EU projects
euroSARC + EEC

Involvement in
ESMO-Guidelines

SPAEN on the
Steering Committee
of RCE

Task Force on
Therapy- and
S.E. Mgmt.

Oct. 2013:
Roundtable on
PAWS-GIST

May 2014:
Roundtable on
Desmoids

Task Force on
Generic Imatinib
15th of July 2015

Collaborations with
EORTC, EMSOS, etc.

European Sarcoma
Centers of
Excellence

Survey among
Member Groups

6th Conference
19th to 21st of Nov.
2015 in Paris





Available at www.sciencedirect.com

ScienceDirect

journal homepage: www.ejcancer.com



Position Paper

Management of sporadic desmoid-type fibromatosis: A European consensus approach based on patients' and professionals' expertise – A Sarcoma Patients EuroNet and European Organisation for Research and Treatment of Cancer/Soft Tissue and Bone Sarcoma Group initiative



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G. Moreau^f, W.T.A. van der Graaf^g, A. Gronchi^h, on behalf of the Desmoid Working
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SPAEN: One out of currently 15 established “Cancer Patient Advocacy Networks” (disease specific)

- CML Advocates Network www.cmladvocates.net
- ELPA - European Liver Patients Association www.elpa-info.org
- Europa Colon www.europacoln.com
- Europa Donna www.europadonna.org
- Europa Uomo www.europa-uomo.org
- ICCPO – Intl. Confed. of Childhood Cancer Parent Org. www.icccpo.org
- IBTA - International Brain Tumour Alliance www.theibta.org
- IKCC International Kidney Cancer Coalition www.ikcc.org
- INCA - International Neuroendocrine Cancer Alliance www.netcancerday.org
- Global Lung Cancer Coalition GLCC www.lungcancercoalition.org
- LuCE – Lung Cancer Europe ???
- Intl. Lymphoma Coalition www.lymphomacoalition.org
- MPE - Myeloma Patients Europe www.myelomapatientseurope.org
- MPNE Melanoma Patient Network Europe www.melanomapatientnetworkeu.org
- SPAEN Sarcoma Patients EuroNet (New Horizons GIST) www.sarcoma-patients.eu

SPAEN driven/supported: Training beyond “silos”...

- **23. – 25.05.2014**
Koop. with ESO-Masterclass
Training for Boards/Chairs of Pat.Networks (Baveno)
- **February 2014 & October 2015**
Koop. with EORTC: 2-day-Course for PAGs
“Understanding Cancer Clinical Research”
Brussels/Belgium
- **9th to 12th of July 2015**
SmartStart Training Course for Beginners
in Frankfurt/Germany



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RCE – Rare Cancer Europe (ESMO) (1)

A world where every rare cancer is properly taken care of

- 20% of all Cancers are RARE = 200 diagnosis
- Over 4 Mill. people suffering from rare cancers in Europe
- Different survival rates: 65% common vs. 47% rare
- RCE is a partnership dating back to November 2008
- Multi stakeholder initiative – grown from 12 to 32 partners
- To overcome the particular challenges that rare cancers pose to patients and their caretakers, physicians and other healthcare workers, the research community, governments and industry
- Challenges were summarised in our 2009 Call to Action

R
CANCERS
EUROPE
E



RCE – Rare Cancer Europe (ESMO) (2)

Some “Highlights”:

- 2008 Consensus Meeting Brussels – 39 Recommendations
- 2009 Call to Action – Signature Campaign
- 2010 EP Meeting “Orphan Drugs” / ESMO Press Conference on RC
- 2011 Awareness Initiatives / Political Meetings
- 2012 WS on Methodology in CT – bunch of activities
- 2013 ESO-ESMO Masterclass, New Steering Committee (ESMO, EORTC, ESO, Novartis, SPAEN)
- 2014 WS on Pathological Diagnosis / EP Meeting on RC Centres of Excellence / Consensus Statements on Pathology

RCE Activity Report will be published soon!

RCE – Rare Cancer Europe (ESMO) (3)

Rare Cancers Europe methodological recommendations for clinical studies in rare cancers: a European consensus position paper.

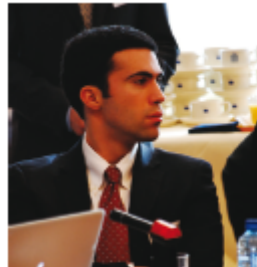
Ann Oncol (2014) doi: 10.1093/annonc/mdu459

- ESMO: Press Conference
- Publication (incl. a lay version)
- Working-Day with EMA – Oct. 2014:
- Working-Day with EMA – April 2014
Chordomas as a model for very RC
- Training-Day in Milano – 1st of July 2015



RCE – Rare Cancer Europe (ESMO) (4)

Rare Cancer Tool Kit...



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ESMO Patient Advisory Working Group (PAWG)

- Established in January 2015
- Serving ESMO with an advisory function
- To integrate the patient's perspective into processes, products and services ESMO offers to the oncology community.
- Engage and collaborate with the ESMO public policy committee
- Support 2015 clinical trials workshop (fall 2015)
- ESMO 2016 Congress (September 2016) – patient advocates program

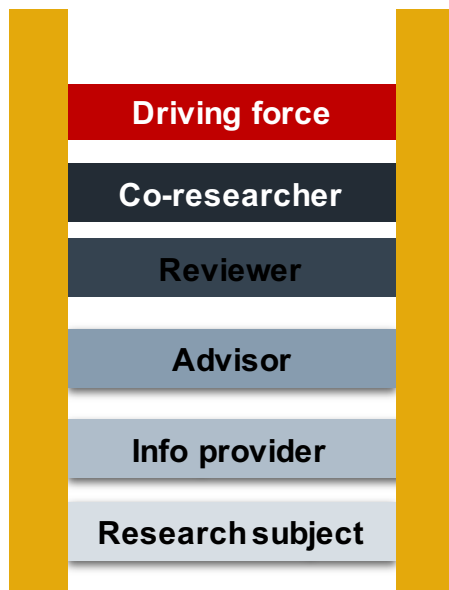
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Patients as partners: partnership model requires a paradigm shift, and more training for patients and advocates



Pre-clinical and clinical research



Source: PatientPartner
FP7 Project (2010)



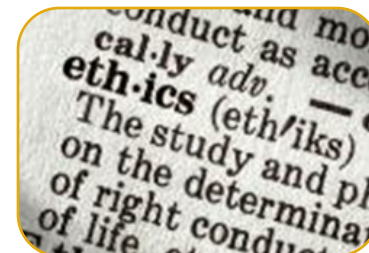
Competent Authorities



Policy Makers/Research Policy



HTA Agencies/Committees



Research Ethics Committees

What is EUPATI?



Sarcoma
Patients
EuroNet



- **A Public Private Partnership** within the Innovative Medicines Initiative Joint Undertaking*
- **A 5-year project**, launched in February 2012
- A patient-led project coordinated by the European Patients' Forum, with EGAN, EURORDIS and EATG in leadership roles
- **A strong multi-stakeholder consortium** of patients' organisations, academia, NGOs and industry – 30 organisations
- **The key pan-European initiative** to build competencies & expert capacity among patients and the health-interested public

* Resources are composed of financial contribution from the European Union's Seventh Framework Programme and in-kind and financial contributions from EFPIA companies

EUPATI empowers patients with education in key areas of medicines R&D



Empower, train and educate patients and patient advocates with objective, credible, correct and up-to-date information about:

1. Discovery of Medicines & Planning of Medicine Development
2. Non-Clinical Testing and Pharmaceutical Development
3. Exploratory and Confirmatory Clinical Development
4. Clinical Trials
5. Regulatory Affairs, Medicinal Product Safety, Pharmacovigilance and Pharmaco-epidemiology
6. HTA principles and practices

+ Patients' roles and responsibilities

EUPATI is developing education targeted at different levels



EUPATI Patient Experts Training Course
-- for expert patients

100
patient
experts

English



EUPATI Educational Toolbox
-- for patient advocates

12.000
patient
advocates

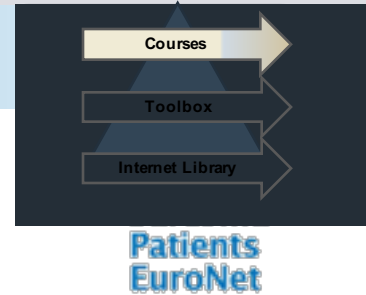
English
French
German
Spanish
Polish
Italian
Russian



EUPATI Internet Library
-- for the health-interested public

100.000
individuals

First EUPATI's Patient Experts Training Course kicked off on 6 Oct 2014



- Open to patients, carers, patient advocates and volunteers
- Two cycles of 50 participants
 - Oct 2014-Nov 2015 (1st 53 trainees),
 - Sept 2015-Nov 2016 (2nd ~50 trainees)
- First course 2014-2015:
 - More than 300 applications for first course were received. Great demand from the community!
 - 55 trainees from 21 countries were selected
 - 46 trainees met in Barcelona after 6 months of e-learning



The EUPATI Internet Toolbox: Educational material in 7 languages (launch end of 2015)



A screenshot of the EUPATI Patient Library website. The header includes the EUPATI logo and the text "European Patients' Academy on Therapeutic Innovation". Below the header is a navigation bar with "Home" and "What is EUPATI About?". The main content area is titled "Patient Library" and features a search bar with the text "Search our library of patient focused educational material" and an example search term "E.g. Clinical trial, HTA, New cardiac treatments". A sidebar on the left lists various topics: Discovery of Medicines, Planning of Medicines Development, Non-Clinical Testing, Pharmaceutical Development, Clinical Development, Clinical Trials, Regulatory Affairs, Medicinal Product Safety, Pharmacovigilance, Pharmacoepidemiology, Health Technology Assessment, and Economics of Healthcare. The main article is titled "Basic Principles of medicine discovery and development" and includes sections for "Drug discovery", "History", and "Current techniques". A diagram at the bottom illustrates the "Lead Driven Discovery" process, showing two interlocking gears: "Target Driven Discovery" and "Lead Driven Discovery".

Glossary

Multilingual encyclopedia

Multimedia

Read or save content offline

Multilingual downloads and toolbox resources

Responsive library content for mobile devices