The European Perspective…

Sunday, 17\textsuperscript{th} 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
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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.
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.
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.
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

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<th>Involvement in Clinical Research as early as possible</th>
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<td>SPAEN on the Steering Committee of RCE</td>
<td>Task Force on Therapy- and S.E. Mgmt.</td>
<td>Oct. 2013: Roundtable on PAWS-GIST</td>
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<td>May 2014: Roundtable on Desmoids</td>
<td>Task Force on Generic Imatinib 15th of July 2015</td>
<td>Collaborations with EORTC, EMSOS, etc.</td>
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<td>European Sarcoma Centers of Excellence</td>
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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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SPAEN: One out of currently 15 established “Cancer Patient Advocacy Networks” (disease specific)

- CML Advocates Network
- ELPA - European Liver Patients Association
- Europa Colon
- Europa Donna
- Europa Uomo
- IBTA - International Brain Tumour Alliance
- IKCC International Kidney Cancer Coalition
- INCA - International Neuroendocrine Cancer Alliance
- Global Lung Cancer Coalition GLCC
- LuCE – Lung Cancer Europe
- Intl. Lymphoma Coalition
- MPE - Myeloma Patients Europe
- MPNE Melanoma Patient Network Europe
- SPAEN Sarcoma Patients EuroNet (New Horizons GIST)

www.cmladvocates.net
www.elpa-info.org
www.europacolon.com
www.europadonna.org
www.europa-uomo.org
www.icccpo.org
www.theibta.org
www.ikcc.org
www.netcancerday.org
www.lungcancercoalition.org
www.lymphomacoalition.org
www.myelomapatientseurope.org
www.melanomapatientnetworkeu.org
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
Topics

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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

RCE – Rare Cancer Europe (ESMO) (1)
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!
Rare Cancers Europe methodological recommendations for clinical studies in rare cancers: a European consensus position paper.


- 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…
Topics

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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

Driving force
Co-researcher
Reviewer
Advisor
Info provider
Research subject

Competent Authorities
Policy Makers/Research Policy
HTA Agencies/Committees
Research Ethics Committees

Source: PatientPartner FP7 Project (2010)
What is EUPATI?

- 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
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
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)

Glossary

Multilingual encyclopedia

Multimedia

Read or save content offline

Multilingual downloads and toolbox resources

Responsive library content for mobile devices