



Sarcoma
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EuroNet

SPAEN AGM

Annual General Meeting 2019

Sunday, 3rd of February 2019

08:00 – 09:30

Radisson Blu Park Hotel, Athens/Greece

AGENDA 08:00 – 09:30 (90 Min.)

Item 1 **Welcome + Introduction**

Item 2 **General check: Who is entitled to vote?**

Item 3 **Report of the Board for 2018**

M. Wartenberg

Outlook: Planned projects/activities – so far

Item 4 **Report of the Financial Director for 2018**

K. Pilgermann

Item 5 **Report of the Financial Auditors for 2018**

M. Wettstein & K. Dolecki

Item 6 **Approval of Accounts / Discharge of the Board**

Members

Item 7 **Requests, Applications, Proposals,**

Any Other Business - End of the AGM

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Sarcoma Patients EuroNet Assoc.

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



General Role Of Patient Organisations...

Main purposes can be defined as related to...

- **Changes** for the individual patient (= support)
- **Changes** for many patients (= advocacy)





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GIST-Patient Groups: Platform for SPAEN...



1st Step (Paris Dec. 2006)



Founding (Bad Nauheim April 2009)

Vision & Mission

VISION

- All Sarcoma Patients 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 Patients and their relatives!

Bone
Sarcomas

Soft Tissue
Sarcomas

Desmoids

GIST



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SPAEN Sarcoma Patients EuroNet Assoc.

International Umbrella-Organisation

- Founded: 2009 under German law (...registered association...)
- Initiator: DE, FR, UK
- Full Members: 44
- Board Members: 7 elected + up to 7 appointed
- Medical Ad-Board: 15 Sarcoma Experts
- Sustaining Partner: Bayer, Lilly, Novartis, Pfizer, PharmaMar
- Research Partner: Blueprint, Deciphera
- More under: www.sarcoma-patients.eu





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Strategic Goal No. 1



To identify problems, challenges, access issues and unmet medical needs in sarcomas. To find solutions and improve the situation by collaborating with leading sarcoma experts, researchers, industry and other relevant international stakeholders/initiatives in an outcome-oriented way.

Projects/Services/Tasks/Engagements



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Strategic Goal No. 2



Sarcoma patients need timely and accurate diagnosis and need to be treated according to guidelines; ideally as early as possible in multidisciplinary sarcoma expert centers. SPAEN advocates and supports the implementation of these structures and international collaboration between these centers.

Projects/Services/Tasks/Engagements



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Strategic Goal No. 3



Clinical research, studies and generating evidence/data are essential parts of the process of developing better and innovative treatment solutions. SPAEN aims to be involved as early as possible in clinical trials, to try to improve patient's access to studies and to support meaningful research – following the specific needs of rare cancer patients.

Projects/Services/Tasks/Engagements



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Strategic Goal No. 4



Sarcoma patients and their relatives need a strong “International Sarcoma Patient Voice” and strong “National Patient Support Opportunities”.

That’s why SPAEN cares for our members (national patient organisations) and encourages the creation of new ones.

Projects/Services/Tasks/Engagements

ACTIVITIES 2018



Core Activities

**SPAEN
Online-Services**

**Newsletter &
Press Releases**

**Annual
SPAEN
Conference**

**Sharing
Best Practice
and Materials**

**Presence at
Important
Conferences**

**Close Collaboration
with Top-Experts and
other Stakeholders**

**Involvement in
ESMO-Guidelines
and EU-Projects**

**Task Forces
and
Roundtables**

**Our Involvement
in Clinical Research
as early as possible**



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Collaborating / Networking





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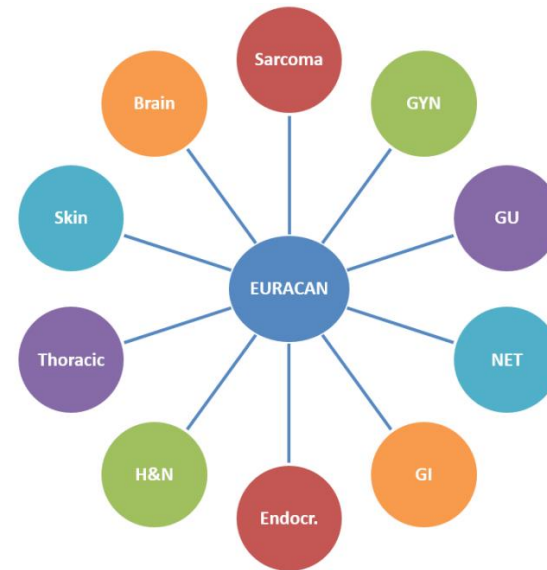
ERNs  European
Reference
Networks **EURACAN**



EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES
Share. Care. Cure.



24 Networks e.g.:
ERN EURACAN
ERN EuroBloodNet
ERN PaedCan

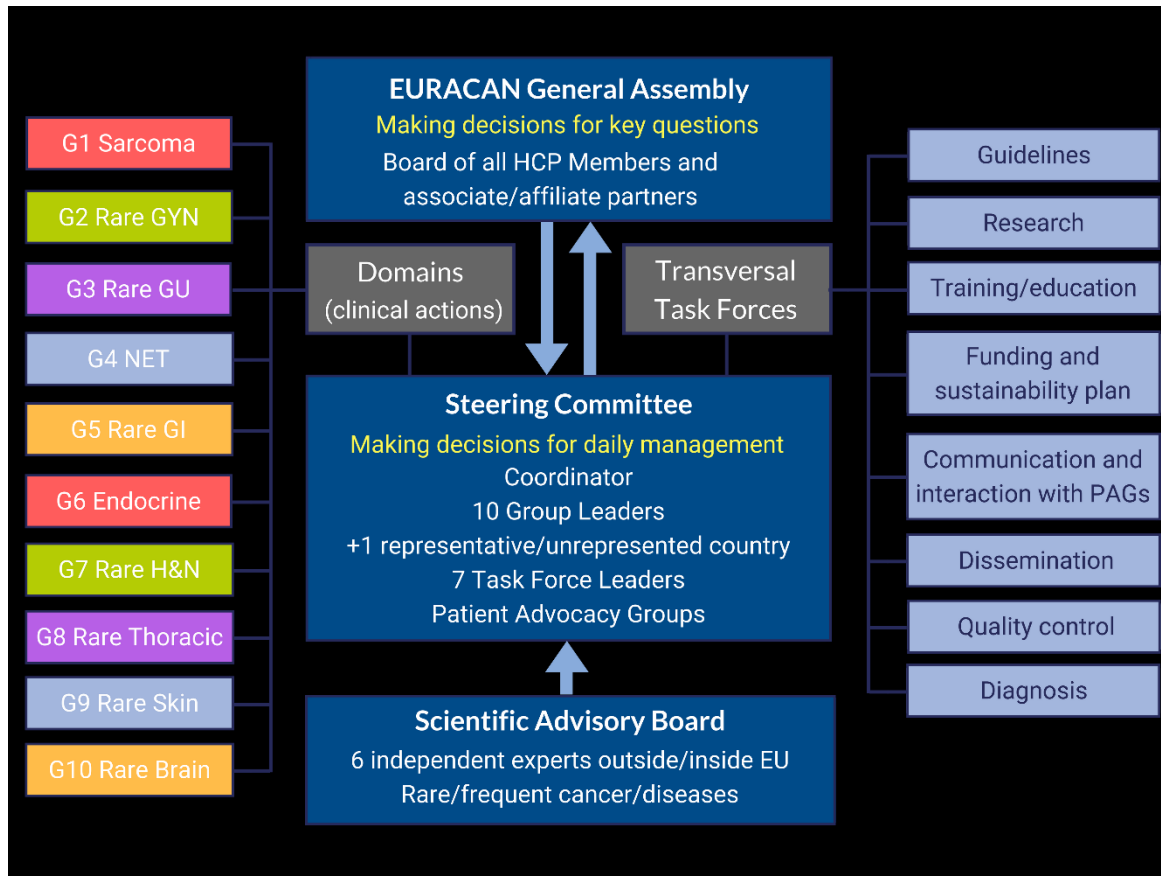


EURACAN

European network for
Rare adult solid Cancer



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SPAEN As Partner In EU-Funded Scientific Projects



The **EEC** is a collaborative project involving 20 European partners and is funded through EUs FP7. It brings together the most active clinicians and scientists in Europe dedicated to improving survival from Ewing sarcoma.



euroSARC (FP7): EUROpean clinical trials in rare SARComas within an integrated translational trial network. The overall objectives is to design, structure and implement 9 innovative clinical trials of different scales, on a multinational level, evaluating novel treatment strategies.

NEW SELNET (H2020): Sarcoma as a model to improve diagnosis and clinical care of rare tumors through a European and Latin American multidisciplinary network.

17/02/2019



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Annual Conferences

Madrid – Berlin – Florence – London – Amsterdam –
Chantilly/Paris – Warsaw – Milan – Athens

Impressions





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8th SPAEN Annual Conference In Milano, Feb. 3 - 4



ESMO GOOD SCIENCE
BETTER MEDICINE
BEST PRACTICE

**ESMO SARCOMA
AND GIST
SYMPOSIUM**

**MILAN ITALY
5-7 FEBRUARY 2018**

Save the date!



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Demoid Consensus Meeting In Milano - June 18



An international update on the management of sporadic desmoid-type fibromatosis:
A European Consensus Initiative between SPAEN and EORTC-STBSG.

Roundtable On Drug Resistance In Sarcomas In Frankfurt – July 20



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New Horizons GIST-Conferences

2012 – Paris (SPAEN)

2013 – Miami (LRG/Alianza GIST)

2014 – Zürich (GIST-Grp. Schweiz/Swiss)

2015 – Miami (LRG/Alianza GIST)

2016 – Sitges/Barcelona (SPAEN)

2017 – New Jersey (LRG/Alianza GIST)

2018 – Vienna (SPAEN) Sept. 5 – 7

2019 – New Jersey (LRG) May 8 - 10





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New Horizons GIST 2018 In Vienna – Sept. 5 – 7





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Participation In **R** CANCERS EUROPE **E**

- **Since 2008: A multi-stakeholder initiative** dedicated to putting rare cancers firmly on the European policy agenda and to implementing 39 recommendations
- During the last 10 years – a lot of activities and projects:
Please find more under: **www.rarecancerseurope.org**
- **SPAEN is a RCE-Partner right from the start** of the initiative.
SPAEN represented the Rare Cancer Patient Community (Networks, Groups) for the last 4 years on the Steering Committee
- Additional working group: Joint Action on Rare Cancers
www.jointactionrarecancers.eu
- Developed by Kathy Oliver (IBTA) & Markus – 2nd time:
RCE-ESMO-ESO Training Course for RC Patient Advocates
Milan, Italy - 01 Dec - 03 Dec 2018



SPAEN Special Involvement (Industry)

- Advisory Boards – disease specific
- SPAEN-Board: Invitations to companies
- Member of initiatives / workstreams / projects / meetings:
 - The future of precision oncology.*
 - Patient involvement in clinical research.*
 - What does it mean for a company - to become more patient centric?*
 - Multi-Stakeholder Working Group on Real World Evidence*



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Participation In **WECAN**

Workgroup of European Cancer Patient Advocacy Networks

WeCan Workgroup of European Cancer Patient Advocacy Networks

- Reasonable agreements between patient advocacy and pharma
- Fair Market Value: Compensation for patients and patient advocates
- WECAN position on further EU integration of HTA (position paper)
- WECAN educational strategy for cancer advocates
- **July 5 – 9, 2019 in Frankfurt SmartStart + ESO MasterClass**



SmartStart



First SPAEN Webinars In 2018...



**SPAEN
Advocacy
Campus
starting now!**

Advocacy Campus: First webinars scheduled!

2019:

**More Webinars will follow.
It will be a pleasure to
receive your suggestions
for interesting topics!**

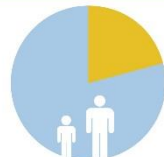


“Sarcoma Infographics” Are Available...

Sarcomas are rare cancers of the bone and connective tissue. It is made up of many „subtypes“ because it can arise from a variety of tissue structures like bone, fat, muscle, nerves, fibrous tissue, blood vessels or deep skin tissue.



1% of all human cancers



10 – 12% of all cancers in children and teens are Sarcomas



12-15% Bone Sarcomas
85-88% Soft Tissue Sarcomas
Incl. GIST (Gastrointestinal Stromal Tumours)
Incl. Desmoids (Aggressive Fibromatosis)



Sarcomas can occur everywhere in the body!



Sarcomas can occur at any age



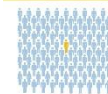
50+ distinct sarcoma subtypes
(WHO Classification)

Management of Sarcomas

Strongly recommended:

- A multidisciplinary approach in specialised sarcoma centres: ▪ Diagnosis
▪ Surgery ▪ Radiation Therapy ▪ Systemic Therapy / Cytotoxic Chemotherapy
▪ Targeted Therapies ▪ Clinical Trials

Sarkome sind seltene Tumoren in Knochen und Weichgeweben. Sie umfassen viele Subtypen, die in unterschiedlichen Körperteilen und Geweben auftreten z.B. in Knochen, Fettgewebe, Muskeln, Nerven, Blutgefäßen, Knorpel- und Bindegeweben.



1% aller Krebsarten sind Sarkome



10 – 12% aller Krebsarten bei Kindern und Jugendlichen sind Sarkome



12-15% Knochen-Sarkome
85-88% Weichgewebs-Sarkome
Inkl. GIST (Gastrointestinaler Stromatumor)
Inkl. Desmoide (Aggressive Fibromatose)



Les sarcomes sont des cancers rares affectant les os et/ou les tissus conjonctifs. Ils se répartissent en de nombreux « sous-types », ces tumeurs pouvant se développer à partir de différents tissus tels que les os, la peau, la graisse, les muscles, les nerfs, les tendons, les vaisseaux sanguins.



Sarkome können in jedem Alter auftreten



1% de tous les cancers



10 – 12% des cancers de l'enfant et de l'adolescent

Behandlung von Sarkomen
Dringend empfohlen:
Interdisziplinäre Betreuung in spezialisierten Sarkom-Zentren
▪ Diagnose ▪ Operation ▪ Bestrahlung ▪ Chemotherapie ▪ T
▪ Klinische Studien



12-15% sont des sarcomes osseux
85-88% sont des sarcomes des tissus mous
(Incl. le GIST ou le Desmoide)



Les sarcomes peuvent se développer sur n'importe quelle partie du corps



Les sarcomes peuvent survenir à n'importe quel âge



+ de 50 sous-types (WHO Classification)

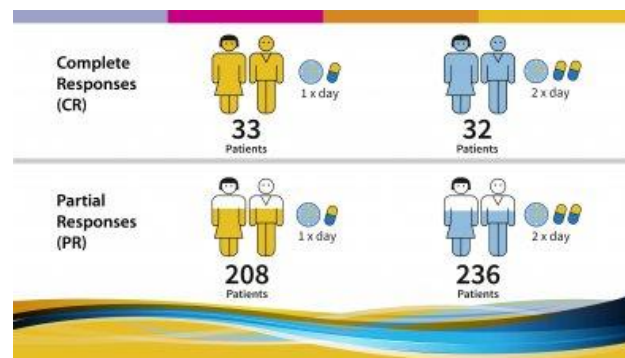
Prise en Charge des Sarcomes

Hautement recommandé :

- Prise en charge pluridisciplinaire dans un centre spécialisé :
▪ Diagnostic ▪ Chirurgie ▪ Radiothérapie ▪ Chimiothérapie ▪ Thérapies ciblées
▪ Essais cliniques

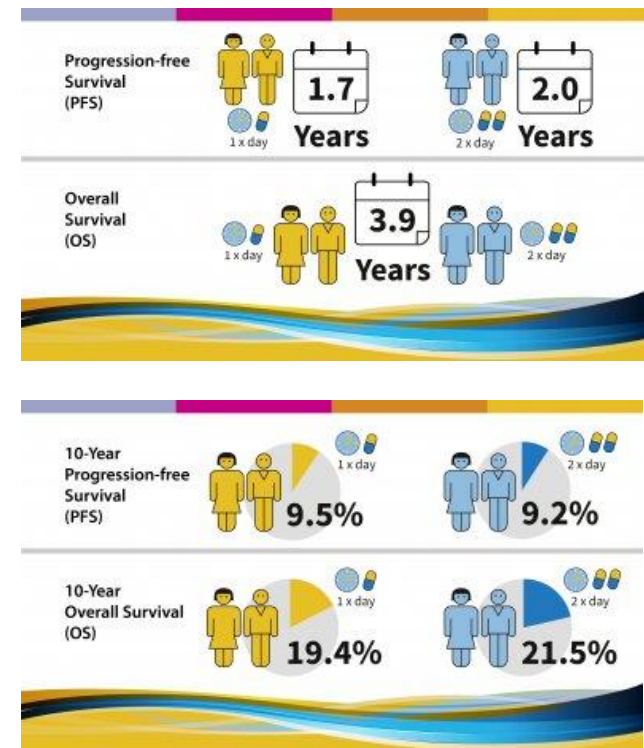


Sarcoma Research Picto-Tool-Box...



A graphical kit that helps us to introduce easily and economically new studies and study results.

In a patient-friendly presentation and language.





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Sarcoma Advocacy In Action Award



2017

1. Friends of Max, India
2. Polish Sarcoma Patients Association
3. Associazione Paola, Italy



2018

1. Das Lebenshaus, Germany
2. PAWS-GIST, UK
3. Patientenplatform Sarcomen, NL



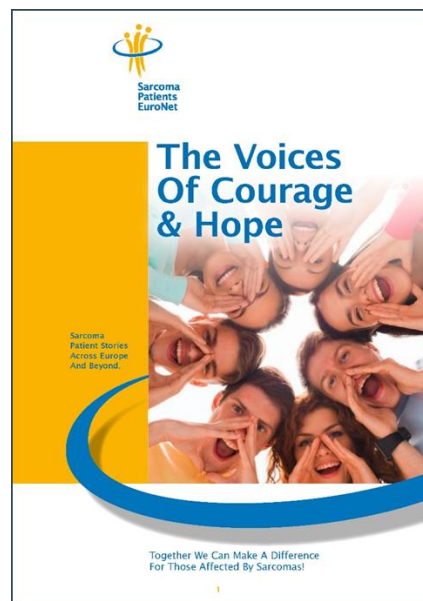


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Offered To SPAEN Members - But Low Feedback...

Book:
The Voices of Courage & Hope
Sarcoma Patient Stories
Sarcoma Group Profiles

STS and Bone Sarcoma Training Course:
What the Patient Advocate needs to know...



SPAEN New Online Resource...

...Launch:
Feb. 6, 2017

www.sarcoma-patients.eu



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

Sarcoma Patients EuroNet

[Advocacy Campus](#) [Training Courses](#) [Webinars](#)

[Learn more about Desmoids](#) [Learn more about GIST](#)



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



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Member Login

Sign up Newsletter

Contact

About us

Our Work

Our Members

Sarcoma Expertise

Sarcoma Research

Sarcoma Reports



NEW HORIZONS
GIST 2016
Conference Report
available.

[Read more](#)



Annual Meeting of
CTOS, November
9-12,
Lisbon/Portugal

[Read more](#)



„Voices of Courage
and Hope” – send
your story now!

[Read more](#)



EMMO Bone
Cancer Youth
Brochure for
download

[Read more](#)



STRASS study:
Now recruiting

[Read more](#)



SPAEN Policy
Paper on “Quality
Care in Sarcomas”
now available

[Read more](#)



www.sarcoma-patients.eu

2018: Total visited pages (blue), total visitors (pink)
Launch of new website: February 6, 2017



Social Media: Facebook & Twitter



Facebook

309 Follower (Jan. 2019)

168 in Jan. 2017
236 in Jan. 2018
(organic growth)



Twitter

576 Follower (Jan. 2019)

134 in Jan. 2017
336 in Jan. 2018
(organic growth)

OUTLOOK - 2019 And Beyond...

Outlook: Topics, That Will Need Our Attention...(1)

- **Central Question**
Member Support: How can we better support our members?
What do you need? What else will help you? What can be developed together?
- **How to find / establish more Sarcoma Patient Groups?**
Driver could be the SELNET project...
Driver could be the Sustaining Partnerships
Driver could be Sessions at Scientific Conferences
- **SPAEN Educational Strategy for Member Organisations...Needs?**
- **New US Sarcoma Coalition: How to collaborate in the future?**
 - Not to reinvent the wheel or doing same activities/projects?
 - Common voice to the Pharma Companies/Researchers?
 - Maybe to develop important projects together?
- We continue to use even more the **new media for SPAEN:**
Videos, Video-Library



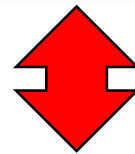
Fields Of Action (Needs Of Our Members?)

Networking/ Collaboration

- Patient Networks
- Medical Experts
 - Industry
 - Regulators

Unmet Medical Needs Solutions Quality

Sarcoma Research



Member Organisation

Information

- Sharing
- New Projects

Education

- Disease Specific
- Research Knowl.
- Capacity Building

Supporting Groups

Founding New Groups

Outlook: Topics, That Will Need Our Attention...(2)

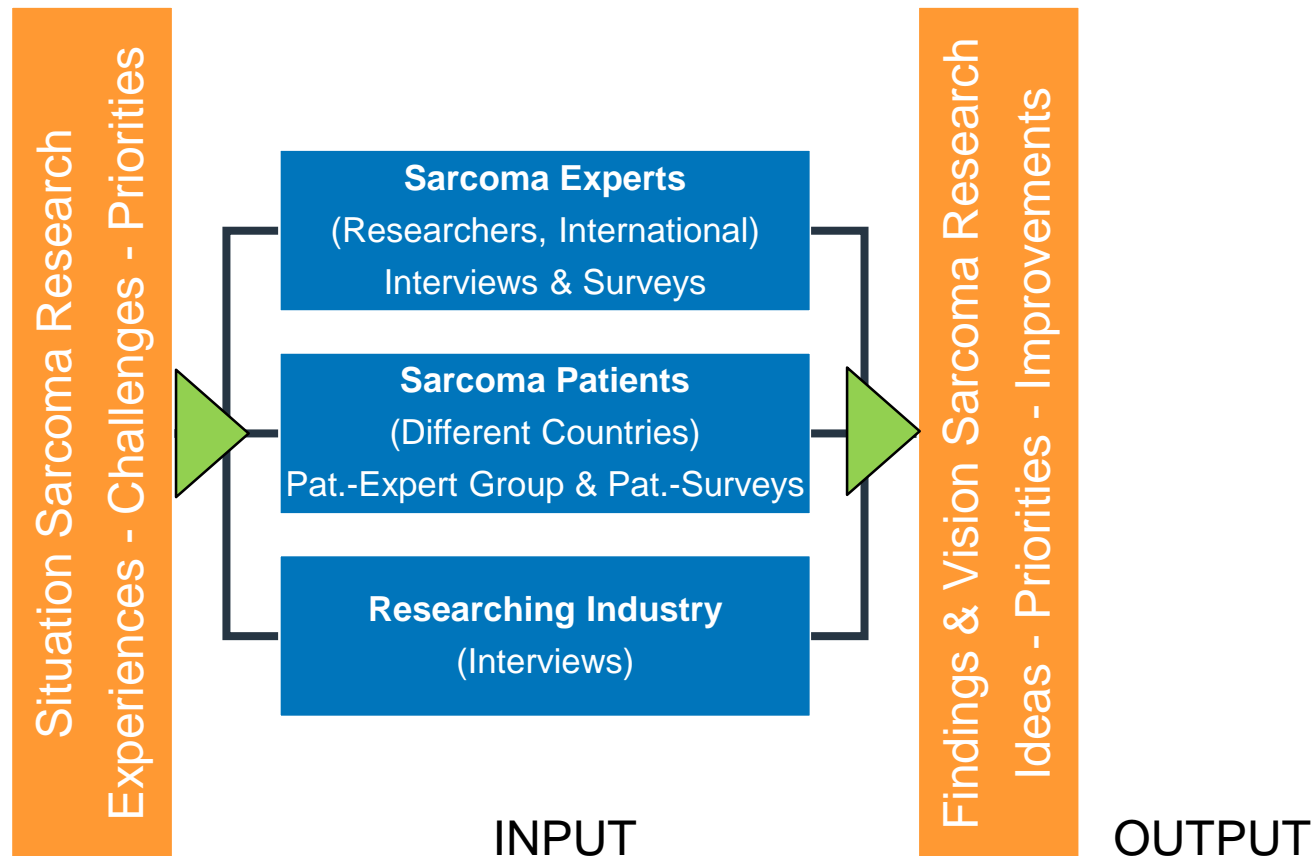
- **Decision Aid Tools: Investigating the potential role of “Decision Aid Tools”**
for sarcoma patients. Ideal start with: GISTaid
A German-European-Project
- Roundtable / Consensus Paper on a rare sarcoma subtype:
Tenosynovial Giant Cell Tumours (TSGCTs/PVNS, etc.)
- **Our Patient-Community:
Being prepared for new therapies?**
Avapritinib (BLU-285) Ripretinib (DCC-2618) Nirogacestat (PF-03084014)
etc.
- Upcoming topic = **“PRECISION ONCOLOGY”**
Larotrectinib (Bayer), Entrectinib (Roche)
Can become a real hype – such as immuno-oncology > false hopes
 - * Precision Oncology in general – meaning, chances, threats
 - * Testing
 - * Positive test: How to deal with the therapy

Outlook: Sarcoma Research...

- **Clinical Trials:** Close collaboration with Pharmas/Experts as early as possible
- **THE NLMSF INTL. LEIOMYOSARCOMA-RESEARCH ROUNDTABLE**
A global roundtable of researchers – with the support of SPAEN
The opportunity to bring 8 – 10 European Experts to the meeting
Sept. 13 – 14, 2019 in Miami/FL
- Establishing a qualified “**Sarcoma Patient Powered Research Network**” (SPPRN)
 - Value? >>> Mission, Objectives, Participants, Training, etc.
 - Could the SPPRN act also as a CAB = Community Advisory Board?
- **Sarcoma Research White Paper:**
Collaborative Project With EORTC-STBSG
 - * How do all stakeholders (patients, experts, industry) assess current sarcoma research?
 - * What are the needs, wishes and priorities of the patients?
 - * What ideas / suggestions / practices are there to make sarcoma research faster and more effective in the near future?



„Sarcoma Research White Paper“ Situation – Analysis – Improvements



Started In 2016: Sarcoma Centers Of Excellence

- Certification Processes on national levels are often driven/influenced by health-policy-issues and compromises. To many clinics (often the wrong ones) are becoming Sarcoma Centers. Often Centers are self-appointed Sarcoma Centers with low qualification.
- We need to get patients as early as possible into Sarcoma Centers – but in the real (good) ones.
- Idea: Sarcoma Patient Advocates (Expert Patients) are developing a valuable, credible and visible certification system on an international level.
A quality brand! International Sarcoma Center of Excellence
(Example: ENETS for NET-Tumors)
- We already developed main criteria.



So – between us: Let's differentiate the very best from the rest!



Outlook: Annual Meeting Planer 2019...

- Feb. 1 – 3 SPAEN Annual Conference Athens, Greece
- Feb. 6 + 7 EURACAN Board Meeting Paris, France
- Feb. 22 Kick Off SELNET EU-Project Sevilla, Spain
- March 14+15 EORTC STBSG Meeting/EGAM Brussels, Belgium
- May 8 – 10 GIST New Horizons Wayne/NJ, USA
- May 15 – 17 EMSOS Florence, Italy
- May 20 – 25 SIOP Conference Prague, Czech Rep.
- May 23 + 24 Pfizer's ArcheoloGIST Warsaw, Poland
- May 31 – June 4 ASCO Chicago/IL, USA
- July 5 – 9 WeCan / SmartStart / ESO Frankfurt, Germany
- Sept. 13/14 LMS-Research Roundtable Miami/FL, USA
- Sept. 27 – Oct. 1 ESMO Barcelona, Spain
- Oct. 17 + 18 EORTC STBSG Meeting Madrid, Spain
- Nov. 13 – 16 CTOS Tokio, Japan
- Early Dec. RCE Traing Course Milano, Italy
- Feb. 2020 SPAEN Annual Conference ESMO / Milano, Italy



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10th SPAEN Annual Conference In Milano, Feb. 2020



ESMO GOOD SCIENCE
BETTER MEDICINE
BEST PRACTICE

**ESMO SARCOMA
AND GIST
SYMPOSIUM**

MILAN ITALY
3-7 FEBRUARY 2018



Save the date!



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Outlook: First Planned Webinars In 2019...

- Isolated Limb Perfusion (ILP) in sarcomas
- Novel therapy options in GIST: What's on the horizon?
- Mutational analysis in GIST: Clinical impact
- Psycho-oncological aspects of cancer
- Special needs of adolescents and young adults (AYA) with sarcomas



Outlook: Projects...

In the future - main types of projects:

- A. A SPAEN defined and funded project – performed/executed by SPAEN and by external service-provider/freelancer...
- B. Collaborative projects such as WeCan projects, where SPAEN is collaborating or is performing the services (time compensated)
- C. A SPAEN defined and funded project – performed/ executed by a national organisation for SPAEN and the international Sarcoma Patient Community...
- D. A project carried out by a national organization – financially supported or co-funded by SPAEN and internationally usable by all SPAEN member organisations...
- E. A project performed by experts or pharmas – with input/experience/ collaboration of SPAEN (ideally time compensated)



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Financial Report 2018

All Member Organisations received the Financial Report prior the AGM

- Financial Directors:
Until Nov. 2014 – Markus Wartenberg
Since Nov. 2015 – Kai Pilgermann
with great support of:
- Das Lebenshaus employee **Tanja Ullersberger**
- No accrual accounting – means:
Income/earnings and costs/expenses
are always reported across years
- 2018 = Preliminary Report
(...not finally approved by the tax consultant...)
- Funding/Sponsoring Activities: Kathrin & Markus



BALANCE SHEET: Account Breakdown 2018

		2018	2017	2016	2015
		€	€	€	€
Account	ASSET MANAGEMENT				
	INCOME/FUNDING				
	Income/earnings - taxfree				
4100	Membership fees (Das LH, AIG)	20,00 €	20,00 €	20,00 €	40,00 €
	Other income/earnings - taxable				
4400/4401	Income Sustaining Partnerships 2017-2019	227.970,00 €	105.000,00 €	112.500,00 €	125.500,00 €
4400/4401	Income Project Funding	40.500,00 €	26.261,99 €	119.000,00 €	55.088,87 €
4401	Income EU-Projects EEC, EUROSARC, etc.	0,00 €	22.793,28 €	0,00 €	7.147,68 €
4402	Income Earnings others/reimbursements	1.087,05 €	1.691,07 €	3.466,87 €	5.545,05 €
4401	Income NH-GIST Conference	Conf. 2018 117.383,76 €	0,00 €	160.040,94 €	0,00 €
		Conf. 2017 26.025,73 €	0,00 €	0,00 €	37.674,99 €
4401	Income Honorarium (Roche RWE Adboard)	0,00 €	665,00 €	0,00 €	0,00 €
4404	Tax Issues	0,00 €	0,00 €	0,00 €	8.360,00 €
	TOTAL	412.966,54 €	156.411,34 €	395.007,81 €	239.316,59 €
4150	Interest Income	0,00 €	0,00 €	208,00 €	0,00 €
		20,00 €	20,00 €	20,00 €	40,00 €
		412.986,54 €	156.431,34 €	395.235,81 €	239.356,59 €

EXPENSES/COSTS									
A.	SPAEN Administration/Operations/Project Mgmt.								
4606	Board Meetings (hotel/location/travelling)	13.235,08 €		15.926,79 €		15.864,33 €		12.718,51 €	
4612	Personnel Costs (freelance basis, no employees) Admin., Secret., Finance/Bookkeep., Proj.-Mgmt.	72.275,61 €		83.234,00 €		64.794,00 €		50.825,95 €	
4705	Expenses website, IT, mailings	4.134,44 €		6.694,48 €		7.777,69 €		4.991,57 €	
4706	Expenses tax consult., final accounting	1.459,40 €		1.508,00 €		1.441,75 €		1.394,90 €	
4712	Banking fees, money transfer	797,87 €		538,45 €		718,55 €		468,41 €	
	Taxes SPAEN Assoc.	25.511,57 €		0,00 €		13.975,85 €		8.220,61 €	
	TOTAL	117.413,97 €	117.413,97 €	107.901,72 €	107.901,72 €	104.572,17 €	104.572,17 €	78.619,95 €	78.619,95 €
B.	SPAEN External Project Expenses/Costs								
4620	5th Annual Conference Amsterdam (2014)	0,00 €		0,00 €		0,00 €		1.696,59 €	
4625	6th Annual Conference Paris (2015)	0,00 €		0,00 €		13.327,52 €		78.983,92 €	
4628	7th Annual Conference Warsaw (2016)	0,00 €		5.726,77 €		52.653,21 €		0,00 €	
4618	8th Annual Conference Milan/ESMO (2018)	40.013,51 €		40.193,34 € pre payment		0,00 €		0,00 €	
4620	9th Annual Conference Athens (2019 Deposit)	18.333,03 € pre payment		0,00 €		0,00 €		0,00 €	
4619	Desmoid Consensus Paper Meeting Milano	4.808,63 €		0,00 €		0,00 €		0,00 €	
4622	NH-GIST Conference (External Europe)	55.396,07 €		0,00 €		106.651,53 €		0,00 €	
4625	Generic Imatinib Meeting Munich	0,00 €		0,00 €		0,00 €		4.193,38 €	
4624	Desmoid Roundtable Frankfurt	0,00 €		4.793,95 €		0,00 €		0,00 €	
	Therapy Resistant Roundtable, Frankfurt	5.334,44 €		0,00 €		0,00 €		0,00 €	
4610	EUROSARC Project (EU Grant)	4.337,36 €		3.500,00 €		4.122,39 €		7.264,16 €	
4611	EuroEwing Project (EU Grant)	4.419,40 €		1.839,47 €		200,00 €		3.084,12 €	
4703	Training Courses (EORTC, SmartStart, etc.)	0,00 €		0,00 €		0,00 €		0,00 €	
4621	Smart Start Training July 2019 (WeCan)	929,12 €		0,00 €		0,00 €		0,00 €	
4613	Presence at medic. conf. ASCO, ESMO, CTOS, etc.	9.226,54 €		10.400,62 €		8.753,36 €		7.636,10 €	
4699	Travelling expenses others	4.057,39 €		4.062,28 €		4.662,10 €		7.089,32 €	
4623	Travelling expenses others	0,00 €		0,00 €		0,00 €		433,46 €	
	Gifts	45,83 €		61,13 €		0,00 €		0,00 €	
	Interest and similar expenses	0,00 €		0,77 €		0,00 €		0,00 €	
4627	Intl. Sarcoma Online Platform (Meet., Transl., etc.)	0,00 €		2.477,65 €		11.262,33 €		0,00 €	
4707	Printed Materials (Relaunch Corporate Design)	431,24 €		652,50 €		3.712,44 €		1.338,66 €	
4711	Translations (english-arabic)	939,51 €		0,00 €		0,00 €		0,00 €	
4707	Funding Research & Quality (Support eSURGE)	0,00 €		3.810,00 €		3.500,00 €		0,00 €	
4629	Policy Work: SPAEN Position Papers	0,00 €		3.693,25 €		1.578,12 €		0,00 €	
4626	Project "The Voice of Courage and Hope"	0,00 €		0,00 €		881,24 €		0,00 €	
4801	Donations (global campaign - Ferdinand)	815,12 €		0,00 €		0,00 €		250,00 €	
	TOTAL	149.087,19 €	149.087,19 €	81.211,73 €	81.211,73 €	211.304,24 €	211.304,24 €	111.969,71 €	111.969,71 €
	ALL COSTS/EXPENSES	266.501,16 €		189.113,45 €		315.876,41 €		190.589,66 €	
	RESULT = ASSETS/SURPLUS/PROFIT	146.485,38 €		-32.682,11 €		79.359,40 €		48.766,93 €	

2019

31.12.2018 Assents on all baning accounts	337.430,97 €
Significant changes in January 2019	
07.01.2019 Pfizer Europe - SP + Projects 2018	20.000,00 €
16.01.2019 Blueprint Medicines - NH-GIST Vienna 2018	8.741,33 €
Jan 19 Expenses/compensation NH-GIST Vienna 2018 to LRG/Alianza GIST	29.885,66 €

AGENDA 08:00 – 09:30 (90 Min.)

- | | | |
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| Item 2 | General check: Who is entitled to vote? | |
| Item 3 | Report of the Board for 2018
Outlook: Planned projects/activities – so far | M. Wartenberg |
| Item 4 | Report of the Financial Director for 2018 | K. Pilgermann |
| Item 5 | Report of the Financial Auditors for 2018 | M. Wettstein & K. Dolecki |
| Item 6 | Approval of Accounts / Discharge of the Board | Members |
| Item 7 | Requests, Applications, Proposals,
Any Other Business - End of the AGM | |

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