



Das Lebenshaus

SARKOME

VEREIN

GIST

SARKOME

NIERENKREBS

LEBEN

Suche ...

SARKOME

IM FOKUS

# Networking Of Patients & Experts **2.0**: Joining Forces Against Sarcomas / GIST!

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Das Lebenshaus e.V.

SPAEN Sarcoma Patients EuroNet eV,

RCE Rare Cancers Europe



## 20% Of All "Cancers" Are "Rare" >>> Every 5<sup>th</sup> Cancer Patient Has A Rare Type Of Cancer...





## Sarcomas ...



- **...are rare**  
(rare complex group,  
super-rare subtypes)
- **... difficult to diagnose**  
(localization, pathologists / biologists  
expertise, differentiation)
- **... difficult to treat**  
(access, expertise, options)
- **... In healthcare systems - underfunded**  
(... like most rare cancers ...)
- **... rarity** limited feasibility  
of **research**/ studies (Evidence!)
- ... but also - learned by now:  
**„models“ for innovative therapies ...**



## > 2.600 Patients: Broad Range Of Negative Experiences...



- For months: Doctors botch
- No, wrong or too late diagnoses and classifications
- Thoughtless and momentous biopsies and resections
- False / wrong performed therapies
- Treatment - not interdisciplinary
- Personally favoured treatments
- Patient "cured" without follow-up
- Statements: No treatment possible
- Study options – not offered
- etc.



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## Essential Tasks Of A Patient Organization ...

### ... CHANGES!

- ...for the **individual** patients =  
Information & Support
- ...for **many** patients =  
Advocacy & Cooperation





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## Das Lebenshaus e.V.: Overview ...

- Org. for patients with rare solid tumours: GIST, sarcomas, kidney cancer
- Founded 15 years ago: June 24, 2003
- Non-Profit Org. = Non-profit association
- Board of Directors + 3 full-time employees
- Meanwhile, more than 4.000 patients/carers (> 2.600 GIST / Sarcomas)
- Local patient groups / contacts
- 2 medical-scientific boards





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## Objectives / Tasks ...



Improving the  
survival of / patients

Sarcomas	<b>Advocacy inside the health system</b>	09/2009
	<b>Clinical Research</b> contribution / participation	
Kidney Cancer	<b>Treatment</b> access, quality, compliance	02/2008
	<b>Patient Empowerment</b> Information >>> individual responsibility	
GIST	<b>Independent, knowledgeable, committed – part of an intl. network ...</b>	06/2003



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## From The Very Early Beginning: Close And Strong Cooperation With Sarcoma-/GIST-Experts ...

German Interdisciplinary  
Sarcoma Group = GISG



Revival of working-groups  
as IAWS and AIO



Development of  
S3 Guidelines (DKG)



Certification Process  
Sarcoma Centres (DKG)



German Sarcoma Registry



Since 2011: German  
Sarcoma Conference







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## After 15 Years: Strategic Planning Process ...

*What is the best "framework" for improving the management of Sarcomas/GIST in the upcoming years - regarding research, quality, supply and patient-support?*

## Our Future Model ... Charitable Foundation...

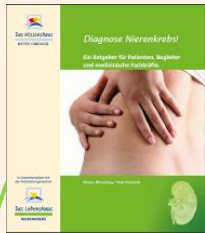
**End of 2018> We will transfer Das Lebenshaus GIST / SARK into an joint organization:**

**„Patients & Experts: Fighting Sarcomas/GIST Together!“**



- GIST, Desmoids, Soft Tissue Sarcomas, Bone Sarcomas / Bone Cancer

## Our Future Model ...



Kidney Cancer – will remain in the association. In the future only:  
Das Lebenshaus Kidney Cancer

For Kidney Cancer Patients >>>  
no changes!!!

Future strategy:  
More voluntary work / teamwork -  
less pharma funding



GIST / Sarcomas „are moving“!  
Future: German Sarcoma Foundation

For GIST-/ Sarcoma patients  
We use synergies!!!

Common future with the  
German Sarcoma-/GIST-experts  
in a new, joint and "non-profit"  
organization...

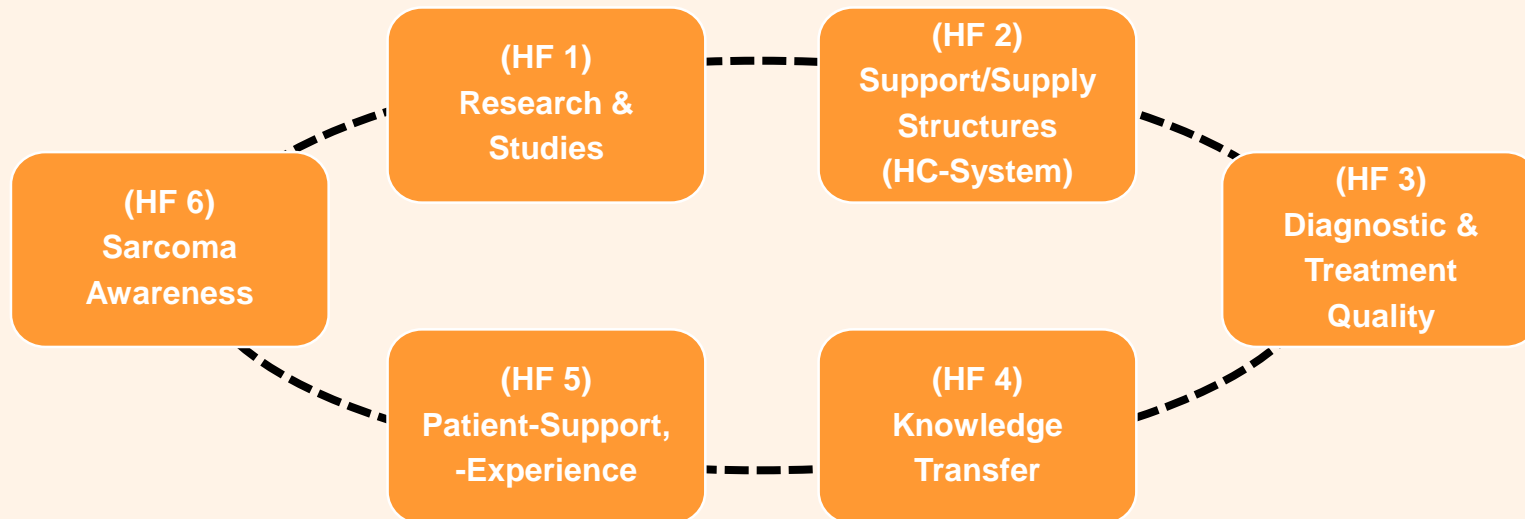
## **Our Vision ...**

**Sarcomas must be curable at some point.**

**Until then, patients & experts in Germany  
are working together in a joint organization  
so that more patients will survive or  
will live longer/better with the diagnosis of a sarcoma...**

## Our Mission ...

Innovative research, high-quality diagnosis and treatment by multidisciplinary sarcoma expert teams and patient-oriented support are crucial factors for better prognosis of sarcoma patients. Patients and experts are fighting together against Sarcomas in six fields of action (HFs):



## Our Patient Areas ...



(HF 1)  
Research &  
Studies

(HF 2)  
Support/Supply  
Structures  
(HC-System)

(HF 3)  
Diagnostic &  
Treatment  
Quality

(HF 4)  
Knowledge  
Transfer

(HF 5)  
Patient-  
Support,  
-Experience

(HF 6)  
Sarcoma  
Awareness



- **HF 5 - Patient Areas:**
  - \* GIST
  - \* Soft Tissue Sarcomas (STS)
  - \* Bone Sarcomas / Bone Cancer
  - \* Desmoids

## Currently: Legal Setup Of The Foundation (Statutes) ...

§ 1 Name, logo, legal form, seat, financial year

§ 2 Objectives of the foundation

§ 3 Non-profit status

§ 4 Foundation assets

§ 5 Foundation funds

§ 6 Foundation structure

§ 7 Board of directors

§ 8 Board of directors: tasks, approach

§ 9 Board of directors: resolution

§ 10 Management

§ 11 Board of trustees

§ 12 Board of trustees: tasks, approach

§ 13 Investments / acquisitions

§ 14 Advisory and working groups

§ 15 Sponsors / donors

§ 16 Liability

§ 17 Foundation supervisory

§ 18 Amendment,  
modification of objectives,  
suspension and merger

§ 19 Asset seizure

§ 20 Inception