

**Patients  
and Experts:  
Fighting Sarcomas  
Together!**

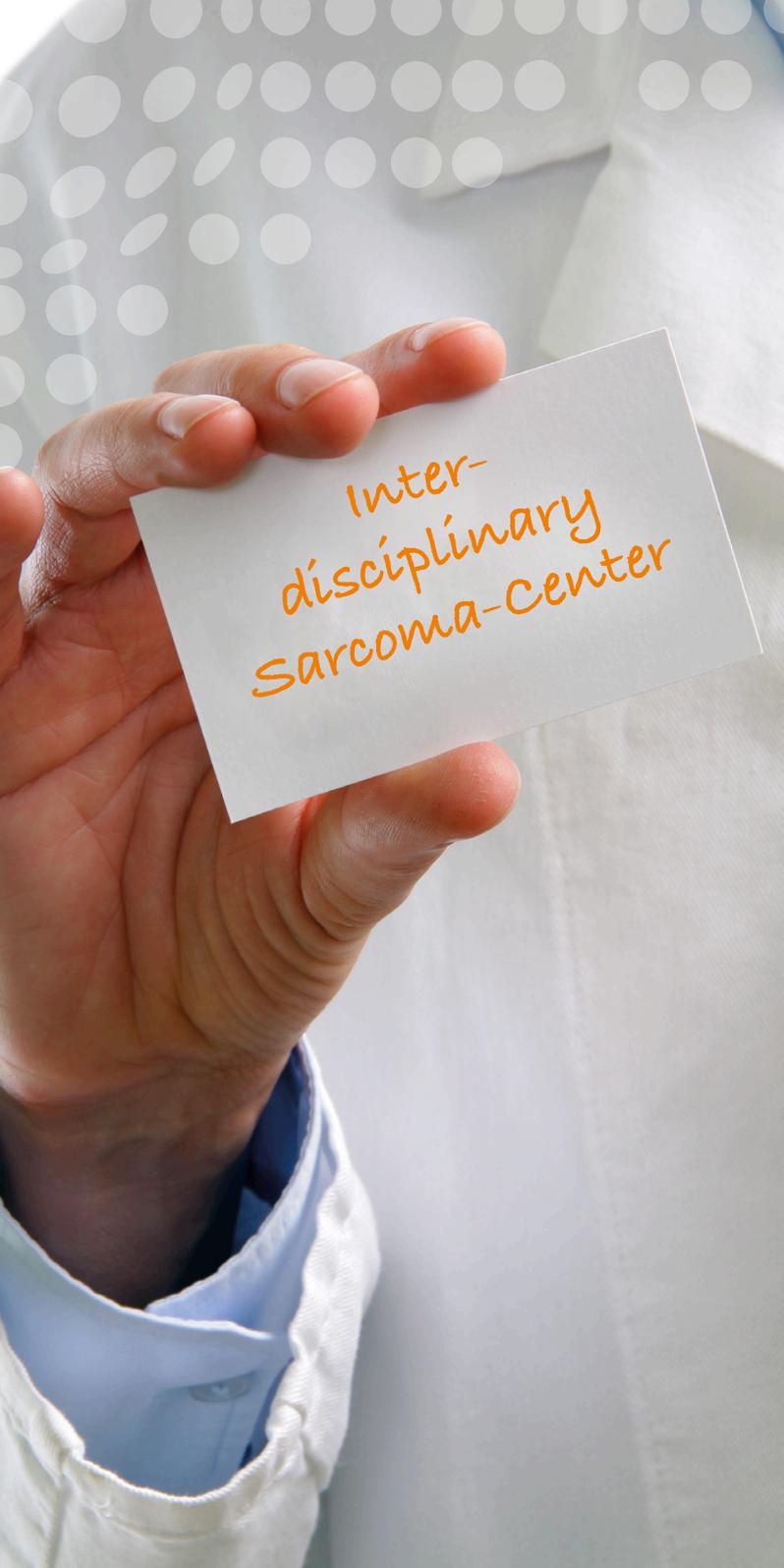


## Sarcomas are not all the same. Sarcomas, a rare group of cancer diagnoses ...

Sarcomas are rare tumors that arise either in the bones or in the soft tissues - for example, the muscle, fat, cartilage and connective tissue. Sarcomas can occur anywhere in the body. There is not just one clinical picture of „sarcoma“. More than 100 malignant types can be classified, with about 20 subtypes, such as liposarcomas, leiomyosarcomas or GIST (gastrointestinal stromal tumors) occurring more frequently.

Some of the different sarcomas vary widely - in terms of their biological behavior, prognosis, and response to different therapies. Many sarcoma subtypes are classified as life-threatening. It is estimated that there are approximately 6,000 new cases of malignant sarcoma in Germany per year (GIST + soft tissue sarcoma + bone sarcoma [often referred to as bone cancer or bone tumors]). This corresponds to about 1 % of all new cancer cases in adults and about 15 % in children in Germany.





## Diagnosis and therapy: Sarcomas belong in the hands of experts!

Unfortunately, the tumors are often detected late, as the possibility of a malignant sarcoma is not thought of at first. Early, correct diagnosis and close cooperation of various experts in the treatment are crucial for the prognosis of the patients.

Thus, there are quite a few studies showing that prompt treatment in interdisciplinary sarcoma centers makes significant differences in the lives and survival of many patients. This justifies our long-standing demand, as well as that of many patient groups and leading physicians worldwide: patients with a suspected diagnosis of sarcoma or GIST should be referred to specialized centers at an early stage. Currently, there are about 20 sarcoma centers in Germany. This means that those affected may well have to travel further distances to be treated in an experienced center.



## Increased research: For more knowledge and better therapy options.

The main pillars of treatment for sarcomas are surgery, radiation and drugs. Depending on the sarcoma subtype and the status of the disease, therapy combinations or special procedures are also used.

While modern, targeted drug therapies are already used for many types of cancer, many sarcomas are still treated with chemotherapy. Therefore, increased research is urgently needed.

**On the one hand**, this concerns basic research to better understand the biology and development of many types of sarcoma.

**On the other hand**, clinical research needs to be done to arrive at more effective therapies through clinical studies, registries and tissue banks. We are committed to supporting this work through participation in studies, an annual research grand award, and through the involvement of experienced patients in planning research at an early stage.



## Patients and Experts: Fighting Sarcomas Together!

As patient representatives and sarcoma/GIST experts have already successfully cooperated in the association „Das Lebenshaus e.V.“ since 2003, it was logical to work even more closely together under one roof in the future.

To this end, 20 donors (Das Lebenshaus e.V., patient advocates and leading sarcoma/GIST experts) established the non-profit German Sarcoma Foundation on October 24, 2019.

Our foundation is a „participatory organization“ in which patients and experts are committed to fight together against sarcomas. Here we devote our energies to the necessary sarcoma research (which has received far too little funding), advocate for better care/treatment quality, and support sarcoma/GIST patients personally.

Our goal is for more patients in Germany with the diagnosis of sarcoma or GIST to survive and to live longer and with a better quality of life!



## The Patient Section: Because no one should be alone with a sarcoma/GIST ...

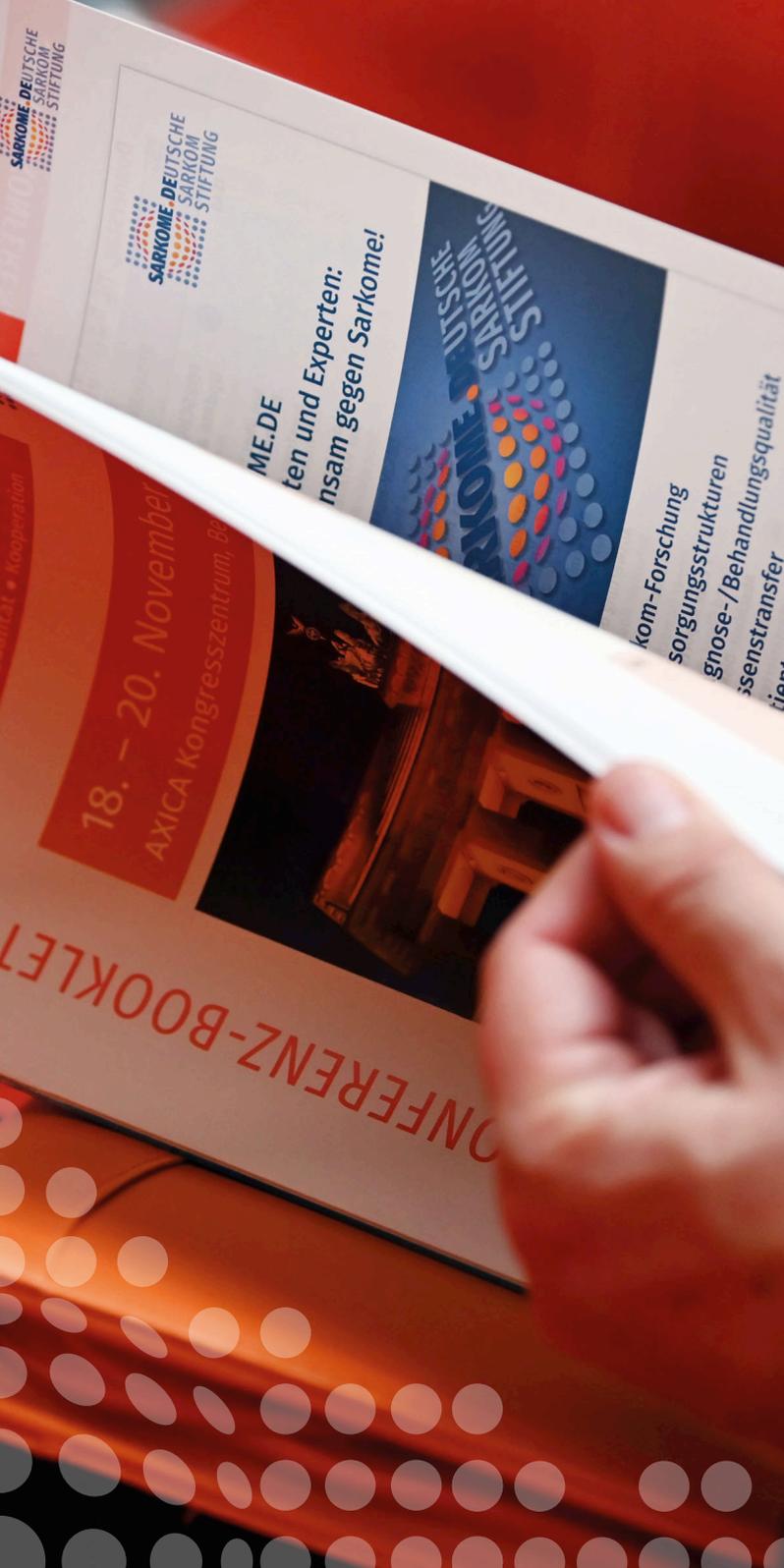
The „Patient Support Section“ of our foundation is the direct successor of the association „Das Lebenshaus e.V.“ Sarcoma/GIST. Our core goal is to achieve changes for sarcoma/GIST patients and their caregivers.

### **Changes for individual patients:**

We offer counseling, information and support - as well as the tangible solidarity of not being alone with such rare diseases. In close cooperation with the sarcoma centers, we strengthen patient knowledge and improve the patient experience. For example, accurate and understandable information is at the heart of our work. In the real world, we provide information in several ways, e.g., through a telephone hotline, brochures, guidebooks, events or in regional groups. In the digital world, we do it through the website [www.sarkome.de](http://www.sarkome.de), our patient forum, the newsletter „WissensWert“ or regular online seminars.

### **Changes for many patients:**

Through the committed representation of interests, we have become a respected „patient voice“ in research, care and health policy.



## The Medical Section: Cooperation = Innovation + Quality + Knowledge Transfer.

We want more patients with sarcomas or GIST to survive and to live longer and better with their diagnosis. This is only possible through close cooperation:

- Between patients and experts.
- Within the sarcoma centers.
- In a network of all sarcoma experts.

Cooperation is the key - nationally and internationally. This collaboration brings more innovation and better quality of care/treatment through the sarcoma community to our patients.

Information, knowledge transfer and collaboration take place throughout the year through services and common activities. Example: We are hosting the 3-day Sarcoma Conference, the annual meeting place for the sarcoma community, since 2011. Here, knowledge transfer and active cooperation take place on the topics of innovation, quality and cooperation:

Between sarcoma experts, experienced patient advocates, the research-based healthcare industry and other professionals.

# What we offer: Services and activities at a glance (excerpt):

## The Foundation:

- Physicians & Patients: Working groups
- Cooperation with all sarcoma centers
- Quality initiatives: e.g., participation in DKG certification and S3 guidelines
- Awareness of sarcomas
- Political representation of interests
- Supporting memberships
- Annual research grand award (25,000 EUR).



## The Patient Section:

- Patient Helpline: 0700-4884-0700  
Personalized information and support
- Patient-Newsletter “WissensWert”
- Regional sarcoma/GIST groups
- **Offline-Services:** Brochures/flyers, guidebooks, events, and more.

- **Online-Services:** Website [www.sarkome.de](http://www.sarkome.de), forum, webinars, videos, Zoom Cafés, podcast and more
- Patient focus groups, position papers on selected topics
- Collaboration in research projects (patients as research partners)
- International collaboration with the umbrella organization SPAGN [www.sarcoma-patients.org](http://www.sarcoma-patients.org).



**Sarcoma  
Patient Advocacy  
Global Network**  
Working together,  
making a difference.

## The Medical Section:

- [www.sarkome.de](http://www.sarkome.de) with two sections – for the public and for physicians only
- Annual 3-day sarcoma conference
- Education and training: e.g., several online symposia per year
- Sister organization for clinical studies: GSG German Sarcoma Group
- International participation: e.g. in ESMO, EORTC, EMSOS, EURACAN, CTOS
- Political representation of the interests of sarcoma patients
- Newsletter “SarkomTicker”



## Help & Support: Commitment has many faces. Maybe yours as well?

Become part of our community and join us in the fight against sarcomas and for those affected by them ...

- By CO-WORKING
- By CO-FUNDING

With your sustaining membership or donation, you support our goals and our work.

The German Sarcoma Foundation is recognized as a non-profit organization.

### Donation account:

**Deutsche Sarkom-Stiftung**

**Volksbank Mittelhessen**

**IBAN: DE51 5139 0000 0073 1063 11**

**BIC: VBMHDE5F**

At [www.sarkome.de](http://www.sarkome.de) you will find many suggestions for „Co-Working & Co-Funding“.

**Deutsche Sarkom-Stiftung**  
**Gemeinnützige Stiftung**  
**Caspar-Bender-Weg 31**  
**61200 Wölfersheim (Södel)**  
**Deutschland/Germany**

**Patient Helpline: 0700-4884-0700\***

\*max. 14 cents/min landline rate, mobile rates may vary.

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