

German Sarcoma Foundation: Short Profile

The German Sarcoma Foundation is a “hands-on organization” in which patients and sarcoma experts fight together against Sarcomas/GIST! The charitable foundation fosters sarcoma research, which is urgently needed and currently underfunded, works on improving quality of treatment & care and directly supports those affected by a Sarcoma or GIST. Thus, the German Sarcoma Foundation will become a highly visible and effective organisation in the German healthcare system that unites all activities of the German Sarcoma-/GIST-Community. Only by pooling the objectives, activities and resources of patients, relatives, physicians, researchers and other healthcare professionals it will be feasible to achieve necessary awareness of rare cancers, such as sarcoma and GIST - to further improve the patient's situation.

Development: On November 18, 2017, the general assembly of the patient organization Das Lebenshaus e.V. (House of Life) decided to re-organize the sections for Sarcoma, GIST and Kidney Cancer patients; always with the most important objective in mind to further improve the situation of patients and their relatives. Since committed patient advocates and leading Sarcoma-/GIST-experts have already cooperated closely and successfully in Das Lebenshaus since 2003, it was a logical to move forward into the future together under one roof. On October 24, 2019 - 20 founders (Das Lebenshaus e.V., 5 Patient Advocates and 14 leading Sarcoma-/GIST-Experts) established the German Sarcoma Foundation.

Vision: Sarcomas must be curable some day! Until then, patients and experts work together in a cooperative, quality-, outcome- and patient-oriented way – for more sarcoma patients in Germany to survive the disease or to live longer and with an improved quality of life.

Mission: Innovative research, high-quality diagnostics, treatment and care by interdisciplinary sarcoma expert teams as well as patient-centred support are crucial factors for a better prognosis of sarcoma patients. Patients and experts are working together on this in six fields of action (HF):

HF1 Sarcoma Research (e.g. participation in and initiation of research, studies, registries)

HF2 Organisation of Care (e.g. sarcoma centres: creation & cooperation)

HF3 Quality of Diagnostics, Treatment & Care (e.g. guidelines and other quality standards)

HF4 Knowledge Transfer (e.g. scientific conferences, education/training)

HF5 Patient Support (e.g. information and support services, patient experience)

HF6 Sarcoma Awareness (e.g. more attention for "rare cancers" such as sarcomas)

Core Values: Teamwork & Networking * Patient- and practice-centred *
Focus on quality * Innovation capacity * Efficiency * Independence

Section „Patient-Support Sarcomas/GIST“ (HF 5):

This section of the foundation is the replacement of the association Das Lebenshaus e.V. Sarcomas / GIST. The main objective is to achieve changes for sarcoma patients and their loved ones.

Change for individual patients: Help patients with advice, information and support services and make them aware that they are not alone with these rare diseases. In close cooperation with recognized sarcoma centres, the foundation aims to strengthen patient competence and to improve patient experience.

Change for many patients: Active advocacy makes this section of the foundation the “strong patient voice” in sarcoma research and in the German healthcare system.

German Sarcoma Foundation: Overview

Registered:	October 24, 2019 RP Darmstadt I 13 – 25d 04.10/1-2019 Non-Profit – charitable status, confirmed November 29, 2019 (FA Giessen)
Statutes:	In German (founding version from July 22 and October 4, 2019) <i>(English translation is commissioned - until end of January)</i>
Bodies of the Organisation:	Board of Directors, Board of Trustees (for advice & support), Patient Experience Boards, Project-/Working Groups
Board of Directors:	PD Dr. Peter Reichardt – Oncologist, Berlin-Buch (Chair) Markus Wartenberg – Patient Advocate, Wölfersheim (Vice-Chair) Karin Arndt – Sarcoma-Patient, Dresden Prof. Dr. Sebastian Bauer – Oncologist, Essen Prof. Dr. Uta Dirksen – Paediatric Oncologist, Essen Susanne Guterath – Sarcoma-Patient, Darmstadt Prof. Dr. Peter Hohenberger – Surgeon, Mannheim Prof. Dr. Bernd Kasper – Oncologist, Mannheim Kai Pilgermann – GIST-Patient, Dinslaken Prof. Dr. Eva Wardelmann – Pathologist, Münster
Address:	Deutsche Sarkom-Stiftung (German Sarcoma Foundation) Caspar-Bender-Weg 31 61200 Wölfersheim, Germany Foundation Office: +49 6036 9836 142 Mobile Phone: +49 170 79 14 989 Patient-Helpline: 0700 4884 0700 Future Website: www.sarkome.de <i>(Under construction)</i> Preliminary Email: info.stiftung.provis@daswissenshaus.de Facebook & Twitter: <i>@Sarkomstiftung</i> <i>(Under construction)</i>
Finance:	Foundation Capital: 160.000,-- EUR Tax-Number: 20 250 84827 VAT-ID: <i>Under application</i>
Donations-Account:	<i>Under application at:</i> Bank für Sozialwirtschaft AG BIC BFSWDE33MNZ IBAN: DE?? 0000 0000 0000 0000 00
Planned Launch-Date:	February 15, 2020