

(Gender clause: In this document masculine and feminine pronouns are used on equal terms. Solely for improved readability was the masculine form chosen for the text.)

PREAMBLE

The term “sarcoma” comes from the Greek “sarcos” meaning “flesh” and “oma” meaning “growth”. A sarcoma is a rare type of tumour that develops either in the bone or soft tissue, i.e. in the muscle, fatty, cartilage and connective tissue. Sarcomas cover a wide spectrum of over 100 different tumour types. These tumours are diverse with a significantly different biological behaviour, prognosis and response to different therapies. It is estimated that the number of new malignant (cancerous) sarcoma cases in Germany is 6,000 per year (GIST + soft tissue sarcomas + bone sarcomas). This equates to approx. 1% of all new cancer cases in adults and approx. 15% of all new cancer cases in children in Germany.

Regrettably, these tumours are often detected late as medical staff do not initially entertain the possibility of a soft tissue or bone sarcoma. However, a correct early diagnosis followed by multidisciplinary co-operation by sarcoma experts experienced in the management of the disease can halt the progression of the disease and increase the patients’ chances of survival. To complicate matters further, sarcomas are not just ONE type of disease. There are well over 100 histological subtypes with around 20 malignant subtypes being most common. Many sarcoma subtypes are classified as life-threatening.

Sarcomas can affect virtually any part of the body which is why the tumour symptoms can vary greatly. Most importantly, every patient should receive an accurate diagnosis as early as possible and be offered the therapy which most suits their specific type of tumour. Patient organisations and leading sarcoma experts around the world stress the fact that patients diagnosed with sarcomas must be treated in specialised centres at all costs. Because there are currently so few specialised sarcoma centres in Germany it is often not possible to care for patients close to where they live.

Particularly symptomatic of most soft tissue sarcomas is that they require space for a swelling or a growth to develop. This means that patients will often not suffer any specific discomfort and therefore will not be diagnosed until after their tumours are already locally advanced or have spread. Sarcomas most commonly spread to the lungs, metastases are less common in the bones or any other organs. Apart from the size and position of the tumour and metastases, tumour differentiation grades are of vital importance when it comes to planning the patient’s treatment. Depending on staging and the subtype of the tumour, treatment could be an operation, radiotherapy, chemotherapy or a targeted therapy (drug-based or systemic therapies, precision oncology) and possibly specialised procedures such as ILP (isolated limb perfusion), hyperthermia or proton beam therapy.

Nowadays, a number of cancer types are treated using targeted drug therapies (targeted therapies, immunotherapies, precision oncology, etc.), whereas the backbone of the systemic treatment of many sarcoma subtypes is still time-honoured chemotherapy. For some subtypes there are either no or only a few approved therapies that can be successfully offered to patients – particularly after disease progression. For this reason more research initiatives are badly needed on a national and international level. On the one hand fundamental research is required to be able to better understand the genetic and moleculobiological causes behind the many sarcoma subtypes. On the other clinical research is needed to develop better therapies with the help of clinical studies and to create a better knowledge base for research and therapies by the setting up of registers and biobanks.

In many European countries – and Germany is no exception – sarcomas are considered an almost “forgotten cancer”. Many patients have no access to information about their specific sarcoma subtype, to a diagnosis and treatment by a cross-functional team of qualified doctors, to experienced sarcomologists’ addresses and to clinical trials – this is particularly true if they have no access to the Internet. Even within

the relevant healthcare systems there is a lack of awareness of the fact that rare cancers such as sarcomas must be treated in specialised centres where clinical outcomes are far better. A number of studies have highlighted that early treatment in a cross-functional sarcoma centre makes a significant difference to the outcome and prognosis for many patients. At the same time healthcare systems waste huge sums of money on inadequate diagnoses and treatments of sarcoma patients by non-specialists.

Our Vision

There will undoubtedly one day be a cure for sarcomas! Until then patients and experts must work together in an engaged, quality-, outcome- and patient-focused fashion as part of an organisation to ensure that more sarcoma patients in Germany survive or live longer and better lives.

Our Mission

Engaged innovative research, high-quality diagnostics and therapies offered by sarcoma experts working in interdisciplinary teams and patient-focused support all play an important role in offering sarcoma patients a better prognosis. Patients and experts are to work together in the following six areas:

- Area 1 Sarcoma Research
- Area 2 Patient-Centred Care Structures
- Area 3 Accuracy Of Diagnosis + Quality Of Treatment
- Area 4 Knowledge Transfer
- Area 5 Patient Support
- Area 6 Sarcoma Awareness

Our Values

- **Teamwork & Networking:** With a high degree of awareness of co-operation...
 - Foundation: Patients and medical professionals working together on equal terms
 - Sarcoma centres: Instead of being a “competitive juxtaposition” they must be focussed on committed co-operation on behalf of the patients and a community based on quality and joint interests
 - Healthcare system: Constructive and result-driven for all stakeholders/partners
 - Internationally: In well-established patient and expert organisations or internationally initiated and supported projects
- **Proximity to patients/centres:** Close to the patient’s real needs and those of the experts/centres
- **Quality awareness:** In all areas, projects, initiatives, measures...
- **Innovation:** e.g. research – jointly with patients, not just about them, result-driven whilst being aware of the available resources
- **Economic viability:** Meaningful and economic use of its finances in line with the Foundation’s mission
- **Neutrality & autonomy:** Despite close co-operation with commercial enterprises

The Deutsche Sarkom-Stiftung (registered office: Wölfersheim) is now incorporated as a Foundation with legal status under civil law.

- The Foundation was launched with the aim of advancing our understanding of oncology, specifically relating to sarcomas, gastrointestinal stromal tumours (GIST) and desmoid tumours, as well as other rare soft tissue and bone tumours (e. g. tenosynovial giant cell tumours (TGCT)/pigmented villonodular synovitis (PVNS) or chordomas). It does this through science and research, promoting public healthcare and public health as well as education, national education and vocational training (including student support).

- We have provided the Foundation with initial assets of EUR 160,000.

The 20 founder members are (in alphabetic order and without academic titles):

Arndt, Karin	Patient advocate, Dresden	EUR 1,500
Bauer, Sebastian	Oncologist, Essen	EUR 1,500
Baumgarten, Christina	Patient advocate, Veitshöchheim	EUR 1,500
Dirksen, Uta	Paediatric oncologist, Münster	EUR 1,500
Dürr, Hans-Roland	Surgeon, Finning	EUR 2,000
Gutermuth, Susanne	Patient advocate, Darmstadt	EUR 2,500
Haller, Florian	Pathologist, Neunkirchen am Brand	EUR 1,500
Hohenberger, Peter	Surgeon, Mannheim	EUR 2,500
Jakob, Jens	Surgeon, Mannheim	EUR 2,000
Kasper, Bernd	Oncologist, Heidelberg	EUR 1,500
Lindner, Lars	Oncologist, Munich	EUR 1,500
Montemurro, Michael	Oncologist, Lausanne	EUR 1,500
Pilgermann, Kai	Patient advocate, Dinslaken	EUR 2,500
Pink, Daniel	Oncologist, Rauen	EUR 1,500
Reichardt, Peter	Oncologist, Panketal	EUR 1,500
Schwarzbach, Matthias	Surgeon, Königstein	EUR 1,500
Tunn, Per-Ulf	Surgeon, Berlin	EUR 1,500
Wardelmann, Eva	Pathologist, Münster	EUR 1,500
Wartenberg, Markus	Patient advocate, Wölfersheim	EUR 2,500
Das Lebenshaus e.V.	Wölfersheim	EUR 126,500

- As an organisation the Deutsche Sarkom-Stiftung could be described as the direct successor to the sarcoma/GIST arm of the non-profit organisation Das Lebenshaus e.V. In addition to the original investment of EUR 126,500 the charity has also given the Foundation additional capital reserves currently estimated to be EUR 320,000. The exact final amount is determined by the kidney cancer representatives' votes and the ensuing parting agreement. The additional capital reserves do not accrue with the Foundation's original assets but are intended for operational set-up and ensuring the Foundation's liquidity.
- The Foundation's governing bodies are the Board of Directors and the Board of Trustees.

Further details are regulated in the Foundation's statutes which are attached and form part of the Foundation's business affairs.

Statutes of the „Deutsche Sarkom-Stiftung“

§ 1 Name, Logo, Legal Form, Registered Office, Financial Year

1. The Foundation is called „Deutsche Sarkom-Stiftung“ and is represented by the following logo:



2. It is a Foundation incorporated in civil law.
3. Its registered office is in Wölfersheim.
4. The Foundation’s financial year corresponds to the calendar year.

§ 2 The Foundation’s Mission

1. The Foundation was launched with the aim of advancing our understanding of oncology, specifically relating to sarcomas, gastrointestinal stromal tumours (GIST) and desmoid tumours, as well as other rare soft tissue and bone tumours (e. g. tenosynovial giant cell tumours (TGCT)/pigmented villonodular synovitis (PVNS) or chordomas). It does this through science and research, promoting public healthcare and public health as well as education, national education and vocational training (including student support).
2. The Foundation intends to accomplish its aims by undertaking work in the six areas detailed below:

Area 1: Sarcoma Research

Objectives: The promotion of sarcoma research by initiating or participating in research projects

- X This can include fundamental research, clinical research/studies, the setting up and keeping of registers and databases, the generation of “real world evidence”, biobanking and the preparation and publication of research results.
- X As modern research tends to rely heavily on international co-operation the Deutsche Sarkom-Stiftung’s international partnerships and its involvement in international networks and projects (such as EU-sponsored projects) are increasingly vital.
- X Research, assessments and measures taken to improve sarcoma patients’ quality of life (combined with other areas such as areas 3 and 5) shall be given a more prominent role than in the past.
- X Supporting sarcoma research also means that patients and experts do everything in their power to jointly generate funds to support research projects.

Area 2: Patient-Centred Care Structures

Objectives: Patients shall be referred to specialised sarcoma centres of excellence comprising of multidisciplinary teams and be treated earlier and more intensely than previously

- X This would, for instance, encompass the support of identifying, setting up and certifying sarcoma centres as well as increasing the public's awareness of them.
- X German sarcoma centres are to co-operate and work more closely under the Foundation's umbrella. The aim is for certified sarcoma centres to engage and co-operate fully as a working, interested and quality-focused community.
- X Certain sarcoma subtypes have "interface problems" linked to other medical specialties (e.g. uterine sarcomas to gynaecologists, skin sarcomas to dermatologists). A joint dialogue and co-operation with the aim of finding solutions will ultimately lead to better patient care.
- X Measures such as patient-centred care research, co-operation concepts for sarcoma centres and referring physicians, health strategy co-operation or measures of support are used to improve patient-centred care structures.
- X A stronger link with European initiatives for the improvement of the treatment of rare tumours such as Rare Cancers Europe (ESMO), Eurordis, the European Reference Networks (ERN EURACAN), Joint Action on Rare Cancer (JARC), SELNET, their successor projects or other useful initiatives should also be established.

Area 3: Accuracy Of Diagnosis + Quality Of Treatment

Objectives: A sarcoma diagnosis must be given earlier and more accurately; treatment and follow-up/monitoring shall follow evidence-based and commonly defined quality principles

- X This would include improving the way sarcomas and sarcoma subtypes are diagnosed to enable a correct diagnosis in pathology laboratories and establishing a second opinion system (reference pathology).
- X The Foundation supports international and national efforts to develop and implement evidence-based treatment guidelines.
- X In order to establish, secure and support quality standards the Foundation may initiate and/or support measures/activities/projects such as
 - * Setting up and keeping disease-specific registers,
 - * Study groups set up to record, coordinate and publish experts' evidence,
 - * Surveys and/or focus groups of medical practitioners or those effected by the disease,
 - * Measuring and publishing quality criteria/results,
 - * Developing uniform processes (e.g. SOPs for sarcoma centres),
 - * Establishing quality conferences to exchange knowledge and experience and prevent errors.
- X The Foundation will investigate how new concepts and measures available as a result of the increasing digitalisation of the healthcare sector could benefit patient-centred care structures and increase the quality and accuracy of diagnoses and therapies.
- X The term "treatment quality" also covers measures aimed at giving all sarcoma patients fair and fast access to innovative sarcoma therapies which have proven to be effective.

Area 4: Knowledge Transfer

Objectives: Supporting the transfer of knowledge and experience within the sarcoma community and ensuring that the next generation of sarcoma experts are educated and trained specifically for the job

X This shall be achieved with measures such as regular conferences/symposia, workshops, training and professional development (in person and online in the form of webinars etc.), mentoring programmes or publications. This is possible for the entire multidisciplinary area “sarcomas” or in a targeted fashion for certain subtypes or areas (e.g. paediatric/adult sarcomas) and for subject-specific target groups/stakeholders (e.g. pathologists, surgeons, radiotherapists, oncologists, psycho-oncologists, etc.).

X Knowledge/experience transfer is also to be offered to target groups/stakeholders, who are directly responsible for non-physician healthcare and treatment provided by nurses, study nurses/study coordinators or experts offering psychosocial support as well as in important complementary areas such as rehabilitation, physiotherapy or prosthetics/orthotics, epidemiology and public health.

Area 5: Patient Support

Objectives: Strengthening of patients’ expertise, improvement of patients’ experience, involvement of patients in research and advocacy of those effected by the disease (patients and partners) within the healthcare system

X Low-threshold, targeted and quality assured information for patients and partners (relatives) via any channel of communication available are vital. This can be achieved through consultations, online and social media offers, print media, events for patients and/or experts, regional patient groups or presence at selected events and conferences.

X People effected by the disease might also find it useful to get advice, information and help about disease-related topics, strengthening patient expertise or becoming dialogue partners in shared decision-making.

X Through close co-operation with sarcoma centres the Foundation will analyse, design and implement initiatives to improve how patients perceive and experience sarcoma centres. This also covers joint patient surveys or measures to boost the patient-centred care teams’ communication skills.

X Patient support also means the early involvement of experienced patient advocates in the conception and design of clinical studies as well as working jointly to improve information flow and communication before, during and following clinical studies.

Keyword: Patients as research partners

X The Foundation also sees itself as the voice of sarcoma patients, especially in connection with their rights, perspectives and interests within the healthcare system.

Area 6: Sarcoma Awareness

Objectives: Raising general and specific awareness of sarcomas (rare cancers) within specific target/dialogue groups based on key topics and messages

Awareness means making specific target/focus groups more conscious of sarcomas. Sarcoma awareness can also simply mean making people more familiar with the topic of sarcomas.

Possible key topics and messages:

- * Sarcomas, the “forgotten”/unnoticed/neglected cancer.
- * The problem area of “rare cancers” using the example of sarcomas.
- * If there is swelling or the symptoms tie in, think sarcomas.
- * Sarcomas should be treated by experts/in sarcoma centres.
- * What does it mean for patients to live with a “sarcoma” diagnosis or survive it?
- * The need to inject more cash into sarcoma research.
-* Patients as research partners particularly in the case of rare cancers such as sarcomas.

In order to do this the Foundation will use modern means of enterprise and marketing communication aimed at specific target groups.

X It is equally important that the topic of “sarcomas” (being part of rare cancers) needs to feature more prominently in medical studies.

3. The Foundation’s Board of Directors determines how the Foundation’s funds should be allocated. More details can be found in the guidelines relating to the allocation of the Foundation’s funds.
4. The Foundation is not obliged to pursue every single mission at all times both fairly and equitably. The Foundation’s committees reserve the right to decide when and to what extent measures taken by the Foundation will be decided on and put into action.
5. Beneficiaries (persons and organisations or establishments) are not legally entitled to receive contributions. The recipients are obliged to account for the appropriate use of the monies and to report in writing to the Foundation.

§ 3 Charitable Status

1. The Foundation directly and exclusively serves charitable purposes as defined in the “Tax-privileged purposes” section of the German Fiscal Code (Abgabenordnung).
2. It acts selflessly and does not primarily pursue goals serving its own economic interests. The Foundation’s funds may only be used for purposes in line with the Foundation’s statutes.
3. No Person can benefit financially from expenditures which are alien to the Foundation’s mission or through a disproportionately high remuneration package.
4. Services to donors pursuant to § 58, item 6 of the German Fiscal Code (Abgabenordnung) are excluded. This means, for example, that the Foundation’s income must not be used for the upkeep of the donors and their next of kin, to maintain their graves or to honour their memory.

5. Pursuant to § 57, paragraph 1, sentence 2 of the German Fiscal Code (Abgabenordnung) the Foundation shall pursue the tax-privileges either itself or with the help of an aide, unless it procures funds pursuant to § 58, item 1 of the German Fiscal Code (Abgabenordnung).

§ 4 Asset Of The Foundation

1. The Foundation's initial assets at set-up amount to a total of EUR 160,000 (in words: one hundred and sixty thousand Euros). With the help of endowment contributions the Foundation aims to achieve assets amounting to at least EUR 1,000,000 (in words: one million Euros). The value of the Foundation's assets shall not be curtailed.
2. Endowment contributions (contributions towards the Foundation's assets) are permissible. Contributions that are not earmarked for a particular purpose due to a disposition of property upon death may be added to the Foundation's assets provided the testator has not specifically requested a timely fulfilment of the Foundation's purpose.
3. Subject to a proper management strategy the Foundation's assets may be regrouped, particularly in relation to retaining values and strengthening earning power. Regrouped profits may be used partially or in full for the purpose of fulfilling the Foundation's mission or added to a regrouping reserve which may be dissolved for the benefit of the Foundation's funds or assets. Regrouped profits are not part of the Foundation's retained assets. This also applies to the reserve funds pursuant to § 62, paragraph 1, item 3 of the German Fiscal Code (Abgabenordnung) and those sums to be added to the Foundation's assets pursuant to § 62, paragraph 4 of the German Fiscal Code (Abgabenordnung).

§ 5 The Foundation's Funds

1. Earnings from the Foundation's assets and from non-incremental contributions and revenues shall be used to fulfil the Foundation's mission in line with tax law requirements.
2. Free or ring-fenced reserves may be set aside to the extent permitted by tax law. Free reserves may be added to the Foundation's assets either partially or in full.

§ 6 The Foundation's Governing Bodies

1. The Foundation's governing bodies are
 - a. the Board of Directors (§§ 7 - 10)
 - b. the Board of Trustees (§§ 11 - 12)

2. (1) The members of the Board of Directors and of the Board of Trustees shall work in a voluntary capacity for the Foundation.
- (2) The members of the Board of Directors, of the Board of Trustees and the donors shall receive no contributions from the Foundation’s funds.
- (3) The members of the Board of Directors and the Board of Trustees shall be entitled to receive reasonable compensation for any expenditures and damages they incur whilst carrying out their roles.
3. The Board of Directors and the Board of Trustees may give each other rules of procedure.

§ 7 Board Of Directors

1. The Board of Directors consists of at least 7 and a maximum of 12 members. It shall elect a chair and a vice chair from amongst its members.
2. The Board of Trustees shall elect the Board of Directors for a duration of 3 years. Re-election shall be permissible. Following the end of term of office the acting Board of Directors shall continue its business until a new Board of Directors has been elected.
Subject to paragraph 3 below the members of the first Board of Directors shall be appointed by the founder members for a total of 6 years to give the Foundation continuity in its formative and start-up phases.
3. Members of the first Board of Directors are the ten founder members of the Foundation listed below:

Medical professionals/experts:	Bauer, Sebastian Dirksen, Uta Hohenberger, Peter Kasper, Bernd Reichardt, Peter Wardelmann, Eva	Oncologist, Essen Paediatric oncologist, Münster Surgeon, Mannheim Oncologist, Heidelberg Oncologist, Panketal Pathologist, Münster
Patient advocates:	Arndt, Karin Gutermuth, Susanne Pilgermann, Kai Wartenberg, Markus	Sarcoma patient, Dresden Sarcoma patient, Darmstadt GIST Patient, Dinslaken Patient advocate, Wölfersheim
4. If a member of the Board of Directors resigns before the end of their term of office, a substitute member shall be elected for the remaining term of office.
5. Following a resolution adopted by the Board of Trustees, members of the Board of Directors may be withdrawn with good cause. Notwithstanding § 12, paragraph 2, sentence 2 such resolution shall be adopted by a three quarter majority of the members of the Board of Trustees.

6. In line with the multidisciplinary approach needed to treat sarcomas the Board of Directors shall ideally consist of representatives of different disciplines – for instance pathologists, radiologists, surgeons, oncologists or radiotherapists.
7. The Board of Directors shall include at least 3 patient advocates in order that they can enrich the work that the members of the Board of Directors and the Foundation do with a broad range of patient experiences. These could be patients, patient relatives, former patients, bereaved or patient representatives.
8. Ideally, the Board of Directors shall jointly define the different responsibilities at Board level (scopes of duty, fields of activity and areas of responsibility) that are necessary for the Foundation and shall allocate these to the relevant Board members. Further details will be taken care of by rules of procedure still to be drawn up.

§ 8 Board Of Directors: Tasks And Method Of Operation

1. The Board of Directors shall be responsible for management and the handling of all tasks.
2. Subject to the Foundation law and these statutes the Foundation's Board of Directors shall fulfil the donors' wishes as effectively as possible. They are tasked in particular with:
 - a. the diligent and economical administration of the Foundation's assets and other means;
 - b. the preparation of the economic plan;
 - c. the adoption of a resolution relating to the use of earnings from the Foundation's assets and non-incremental contributions;
 - d. the preparation of the annual accounts or annual statement of account including a financial statement and
 - e. the annual preparation of a report on the fulfilment of the Foundation's mission.
3. If and insofar as the fulfilment of the Foundation's mission is not thwarted and if the Foundation's financial situation allows, the Board of Directors may, if remunerated fairly, impose the tasks incumbent upon them on third parties (e.g. managing directors, company secretaries, coordinators, etc.) who answer to the Board and are bound by its instructions. Members of the Board of Directors must not be employed by the Foundation.
4. The Board of Directors shall represent the Foundation in court and out of court with at least two of its members. One of these members must be the Board's chair or vice chair.
5. Property and legal transactions which the Foundation will be bound by which amount to more than EUR 25,000 are subject to the Board's prior agreement based on a simple majority.

§ 9 Board Of Directors: Adoption Of Resolutions

1. The Board shall adopt its resolutions based on a simple majority of its members in attendance. The Board shall have a quorum if at least 50 % of its members are in attendance. In the event of a tie, the member elected to chair the meeting and chairing the meeting shall have the casting vote.
2. If a resolution is to be passed by circular mail (postal mail, fax, email, etc.) a quorum of at least three quarters of the Board members is required.

§ 10 Management

1. The chair or the vice chair of the Board shall convene meetings as often as is deemed necessary for the proper management of the business. This shall, however, require at the very least two meetings a year at which members are in attendance. Such meetings shall only take place if an agenda has been distributed and the meeting announced at least 4 weeks in advance. Additional Board meetings may also take place using modern means of communication (audio, video, etc.). A Board meeting shall also be convened if at least one third of its members have asked for it.
2. Minutes shall be taken of the Board meetings and signed by the chair of the meeting and the person taking the minutes. Resolutions shall be recorded verbatim. Every member of the Board of Directors and the chair of the Board of Trustees shall be made aware of the minutes.
3. Within nine months of the end of the financial year an annual statement of account, a progress report and a financial statement shall be submitted by the Board of Directors to the supervisory authority.

§ 11 Board Of Trustees

1. All founder members, irrespective of their membership of any other committee, shall be life members of the Board of Trustees. A founder member may renounce being a member of the Board of Trustees at any time. The management of a legal entity may send a representative.
2. Members of the Board of Trustees may appoint further persons into the Board of Trustees for a 4-year-term. They shall appoint further persons to the Board of Trustees for the duration of the 4-year-term if and to the extent that the number of members in the Board of Trustees has dropped to below 10. Additional donors and other persons who are linked to the Foundation in a professional, non-material or material way may be considered as members of the Board of Trustees. Re-appointments are permissible.
3. Members of the Board of Trustees shall elect one of their own as chair or vice chair for the duration of 4 years.

§ 12 Board Of Trustees: Tasks, Adoption Of Resolutions

1. The Board of Trustees elects, advises and supports the Board of Directors, recalls members of the Board of Directors for an important reason and adopts the fundamental resolutions given in § 18. Professional and social groups represented on the Board of Trustees shall promote the Foundation's mission through an exchange of ideas across varied disciplines and interests. They shall also promote and strengthen public awareness of multifaceted sarcoma diseases and the research needed to improve treatments. The Board of Trustees also supports the work of the Foundation by maintaining contact with potential funding organisations and donors/sponsors.
2. The Board of Trustees has a quorum if more than half of its members are in attendance. Resolutions are passed with a simple majority of all votes cast. A resolution by circulation is permissible. The Board of Trustees holds its meetings as necessary. The chair shall send out invites to the Board meeting including the relevant agenda in good time.
3. Minutes shall be taken of the Board meetings and signed by the chair of the meeting and the person taking the minutes. Resolutions shall be recorded verbatim. Every member of the Board of Trustees and the Foundation's Board members shall be made aware of the minutes.

§ 13 Holdings/Acquisitions

1. The Foundation may invest in other foundations, organisations, associations and companies and acquire them or integrate their assets into the Foundation's.
2. Two main recommendations should be adhered to:
 - * They need to be non-profit foundations, organisations, associations and/or enterprises.
 - * Their scope of activity should match or complement the Foundation's mission and the prevailing areas the Deutsche Sarkom-Stiftung is involved in.
3. Prior to deciding on any holdings or acquisitions the Board of Trustees, the tax authority in charge and the competent supervisory authority must be heard.
4. A decision in favour of a holding or an acquisition requires a three quarter majority in the Board of Directors.

§ 14 Advisory Committees And Working Groups

1. The Foundation's Board may appoint and dismiss advisory committees and working groups.
2. Rules of procedure for advisory committees and working groups shall be drawn up which define their make-up, chair, goals, tasks, meetings, resolutions and documentation.
3. Members of the advisory committees and of the working groups shall work for the Foundation in a voluntary capacity. They shall receive no contributions from the Foundation's funds. They shall be entitled to receive reasonable compensation for any expenditures and damages they incur whilst carrying out their roles.

§ 15 Donors/Sponsors

1. In order to support the Foundation's mission and to contribute to its current financing the Foundation may publicly create two groups of donors/sponsors:

A. Private donors/sponsors

These can be individuals such as patients, partners (relatives), cured/former patients, surviving dependants, colleagues from any medical profession, benefactors, other stakeholders, etc.

B. Institutional donors/sponsors

These may be institutions drawn from the following:

- Enterprises who have a direct connection with sarcomas (such as pharmaceutical companies, medical equipment manufacturers, prosthetics manufacturers, health insurance companies, etc.)
 - Enterprises who do not have a direct connection with sarcomas and clinics, doctor's surgeries, rehabilitation centres, associations, organisations, other foundations, etc.
2. Any donors'/sponsors' mission in connection with subsidies and donations are taken into account by the Foundation in as far as they correspond to the mission of the Foundation as defined in § 2, paragraphs 1 and 2 of these statutes.
 3. The Foundation undertakes to keep all donors/sponsors abreast of any developments within the Foundation by sending them a link to the (offline or online) annual report/progress report.
 4. Any further details such as the admittance of donors/sponsors, funding, rights and obligations, termination of funding, etc. are regulated by separate donor/sponsor statutes.

§ 16 Liability

The members of the Foundation's governing bodies shall be obliged to duly manage the Foundation's assets. In the event of an intentional or grossly negligent breach of their obligations, they shall be obliged to pay damages to the Foundation without prejudice to liability provisions in other laws.

§ 17 Control Of The Foundation

The Foundation is governed by state control in accordance with the applicable foundation law.

§ 18 Changes To The Statutes, Mission Changes, Revocation And Consolidation

1. Changes to the statutes are permissible insofar as they appear necessary to adapt to changed circumstances. The Foundation's tax advantages may not be affected or repealed by changes to the statutes.
2. The Foundation's dissolution or consolidation with one or more foundations may be considered if circumstances no longer allow the continued and sustainable fulfilment of the Foundation's mission and also if the sustainable fulfilment of a new mission of the Foundation cannot be considered. The newly consolidated Foundation shall also benefit from tax advantages.
3. Decisions reached subject to paragraphs 1 and 2 shall be made by the Board of Trustees and require notwithstanding § 12, paragraph 2, sentence 2 a three quarter majority amongst the members of the Board of Trustees.
4. For changes to the statutes, the Foundation's dissolution or consolidation with one or more foundations to come into effect approval is required from the relevant regulatory authority.

§ 19 Accumulation Of Assets

In the event that the Foundation shall be dissolved or tax advantages cease to exist, the Foundation's assets will fall to a legal entity under public law or another tax-privileged body to be determined by the Foundation's Board of Directors and used for the promotion of science and research in oncology – specifically relating to sarcomas, gastrointestinal stromal tumours (GIST) and desmoid tumours, but also to other rare soft tissue and bone tumours (e.g. tenosynovial giant cell tumours (TGCT)/pigmented villonodular synovitis (PVNS) or chordomas).

§ 20 Coming Into Effect

These statutes come into effect the day the Foundation is approved. All founders of the Foundation are familiar with the draft of the Foundation's business affairs and the statutes of the Deutsche Sarkom-Stiftung in their final version dated 22 July 2019 and they have given Mr Markus Wartenberg their authority to sign these statutes on their behalf:

Wartenberg, Markus Wölfersheim _____

(Markus Wartenberg on behalf of the founder members of the Foundation)

Charity Das Lebenshaus e.V. Wölfersheim _____

(Markus Wartenberg on behalf of the Board of Directors)

Exhibits: Powers of attorney of the Foundation's founder members – Markus Wartenberg

 Powers of attorney of the Foundation's founder members – Solicitors Haas & Hass