Sarcoma
Patient Advocacy
Global Network

Working together,
making a difference.

Strategy and goals 2021-2026

Quo vadis, SPAEN?

SPAEN was founded in 2009 as a European network of patient groups for GIST, sarcomas and desmoids. In a little over a decade, the organization has achieved a great deal, established important contacts, and implemented many projects that directly benefit patients. In addition, we have grown from the 11 founding members in Europe to nearly 60 member organizations (as of 2023) from around the world.

After a good 10 years, however, the board and team of SPAEN then asked the essential question of where the journey should go for the organization in the coming years — and whether the path taken with the foundation in 2009 is still the right one.

SPAEN's leadership team took the first steps in 2019/2020 to initiate a planning process. Through surveys and meetings, a SWOT analysis was conducted and a multi-step process was used to review the strategic direction and goals of the organization.

In late 2021/early 2022, the new strategic plan with revised vision, mission, values, and strategic goals was established.

In addition, to further underpin our strategic alignment as a global organization, we decided it was necessary to change our name.

On the following pages we present our goals, mission, and vision for the years up to 2026.

SPAEN becomes SPAGN

SPAEN had opened the network to member organizations outside of Europe in 2016. The leadership and the members of SPAEN felt that it was time to make the global work SPAEN had been doing for a number of years already more visible.

Thus, during the Annual General Meeting in June 2022, the member organizations of SPAEN voted to rename the association from Sarcoma Patients EuroNet (SPAEN) to Sarcoma Patients Advocacy Global Network, SPAGN for short.

It was the aim to reflect the global work of SPAEN/SPAGN in the name of the organization.

In this context, the “face” of the organization, our website, was also revamped and given a new, global URL. Find out more at www.sarcoma-patients.org.

In 2022, almost 60 member groups from all five continents gathered under the umbrella of SPAGN, representing a strong and united voice for sarcoma patients around the globe.

Sarcoma
Patients
EuroNet

SPAGN’s new vision and mission

As part of the strategic planning process, the vision and mission of the organization were revised:

Our Vision

Our vision is that one day sarcomas will be preventable or curable. Until then, patients, experts and other stakeholders are working together globally to

- drive sarcoma research
- improve early and correct diagnosis
- secure timely access to interdisciplinary expert-care and
- provide patient-oriented information and support.
- It is our aim to make sure that more sarcoma patients live longer with a better quality of life.

Our Mission

SPAGN is the global network of Sarcoma Patient Advocacy Organizations who strengthen one other and provide a common, international and influential patient voice. Our joy and passion in working across borders drive us to achieve necessary change together with our collaborators.

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Strategic Goals

The strategic goals were also put to the test and adjusted.

The focus of our work in the future will be on the following goals:

- **Influential Organisation:** Becoming a more influential organisation that is well prepared for the future.
- **Active Members:** Growing the presence and impact of SPAGN through the sum of strong, committed, and active members.
- **United Global Patient Voice:** Engaging as many countries as possible in realising our vision and mission.
- **Addressing Unmet Needs:** Setting up strategies and activities in areas of specific unmet need, such as “Primary Bone Cancer” (to 2026).
- **Access To Qualified Care:** Advocating for sarcoma patients to have access to qualified diagnostics, treatment and follow up.
- **Strong Partners in Research:** Bringing the patients voice to sarcoma research: seeking to partner in research which is inclusive of the needs and priorities of patients.
- **Sarcoma Awareness:** Raising awareness of sarcoma with selected messages to specific target groups, coordinated internationally.

Please note: The goals listed here are in no particular order and do not reflect the order of our priorities.

Goal 1: Influential Organisation:

Becoming a more influential organisation that is well prepared for the future.

SPAEN has always been an organisation that is strongly characterised by voluntary commitment as well as joy and passion for international collaboration, among each other and with the medical experts. The aim was always to think and act internationally and across all indications. Most of the “doers" have been engaged for SPAEN – despite their enormous workload at the national level.

To lead SPAEN/SPAGN successfully into the future, we need:

- During the next 2-4 years: The preparation for a generation change towards a younger (voluntary) leadership (board members)
- More human resources (employees or freelancers)
- Furthermore, professional and well-functioning external communication
- Software tools to communicate internally and to work better and more efficiently together
- A healthy financial basis

Goal 2: Active Members

Growing the presence and impact of SPAGN through the sum of strong, committed, and active members.

The basis of SPAGN is the network of currently nearly 60 member organizations. Each organisation has its individual profile and stage of development.

The future of SPAGN lies:

- In a great (active) collaboration among the members of this network. SPAGN must be a "hands-on organisation" - not just a network of "consumers".
- Answering the questions: What can SPAGN do for its members, what can the members do for SPAGN, for the global community?
- Strengthening of the individual members by sharing experiences, projects and by offering qualified training and education.

  Education and training, especially in the areas of
  - sarcoma, medical and research knowledge
  - knowledge for the further development of the member organisations and their leaders
- A working group will assess learning needs and develop training offers.

Goal 3: United Global Patient Voice

Engaging as many countries as possible in realising our vision and mission.

SPAEN is no longer European, but international. This should also be visible in our name: Sarcoma Patient Advocacy Global Network (SPAGN).

There are still many countries around the world in which patients do not have access to quality sarcoma care and in which no sarcoma patient groups/representatives exist. We know from experience: Such patient groups only arise when patients take the initiative or medical professionals offer support or collaborate. It's not SPAGN's aim to set up our own "branches" in certain countries, but to foster, mentor and help grow those groups organically.

We will therefore pursue the following strategy for the future:

- Wherever patient groups exist/arise, we will help with experience, knowledge and mentoring within the resources SPAGN has
- We inform experts about the role of patient representatives, the benefits of working with patients and hope to motivate them to initiate first contact points or grassroots groups in individual countries
- We establish resources to provide information and knowledge

Goal 4: Addressing Unmet Needs

Setting up strategies and activities in areas of specific unmet need, such as “Primary Bone Cancer”.

SPAEN was initiated in 2009 by a strong GIST patient community and the rapid expansion towards soft tissue sarcomas and desmoids. Until around 2018, the topic of bone sarcomas was underrepresented at SPAEN.

It is important to be significantly more active here. In the case of bone sarcomas, this mainly affects the paediatric and the area of AYA (adolescents and young adults).

In order to be more active here we will need in the future:

- A special “Working Group Bone Sarcomas”, that defines what SPAGN should do in the short, medium and long term
- Address the younger patient population through different ways of communication and media channels
- Closer relationships / collaboration with organizations such as EMSOS and SIOPE

While Bone Cancer is an ongoing priority there will be ‘roundtables’ and ‘time-limited workshops’ to address other needs.

Goal 5: Access to Qualified Care

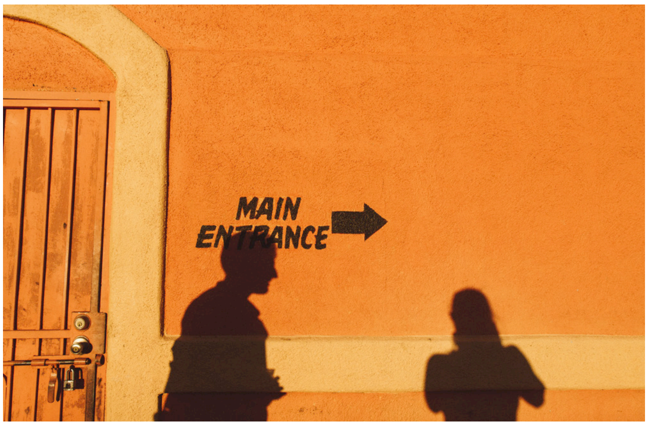
Advocating for sarcoma patients to have access to qualified diagnostics, treatment and follow up.

We know that highly qualified care for sarcoma patients should ideally take place in multidisciplinary sarcoma teams, centres or networks. Patients who are properly diagnosed early and treated in sarcoma centres often have a much better prognosis of being cured or surviving longer with such a diagnosis.

There are not many countries that have designated sarcoma centres - even less often there are “national networks of (certified) sarcoma centres”. “Modern oncology” is found almost exclusively in high income countries with a high standard of living. Low- and middle-income countries often lag behind.

We advocate for:

- **Access to expert care:** We want sarcoma patients everywhere to have access to “sarcoma expert care”, if possible in their home country, with a definition of minimum requirements for sufficient sarcoma care, expectations from the patient perspective for interdisciplinary sarcoma centres
- **Access to the latest care:** This means access to innovations and approved treatments, but also effective treatments that are available but may not yet be approved in their home country



Goal 6: Strong Partners in Research

Bringing the patients voice to sarcoma research: seeking to partner in research which is inclusive of the needs and priorities of patients.

The number of therapeutic innovations for the treatment of many sarcoma subtypes is very limited. Very often, old chemotherapeutic agents are the only options. Research into sarcomas is underfunded and often does not take place in a targeted manner.

Thus, we need changes in sarcoma research through the early involvement of patient representatives in sarcoma research: "Patients as Sarcoma Research Partners":

- Based on patient needs and unmet medical needs, patients and experts should jointly define the research priorities in most subtype. ("Research agenda")
- Patient representatives must be involved in the planning and development of research projects and clinical trials at an early stage. This will require training for patient representatives: We will provide education and training for our member organizations in the field of sarcoma/clinical research
- We advocate for new ideas/ways on how sarcoma research can be carried out faster and more efficient in the future

Goal 7: Sarcoma Awareness

Raising awareness of sarcoma with selected messages to specific target groups, coordinated internationally.

Awareness about sarcomas is important. However, sarcoma awareness campaigns for sarcomas should be targeted and aim to foster changes for sarcoma patients.

Sarcomas are far too rare and SPAGN's human and financial resources do not suffice to run big international awareness campaigns.

Key questions will be:

- Who are the right target groups for awareness activities?
- What are the right topics / messages that really can change something?
- How do we get coordinated and affordable power?
- Which (affordable) channels can we use - e.g. social media / press, etc.?
- Could something like this be coordinated on an international basis – e.g. via SPAGN - with a special awareness week in July?

It is planned to establish a Task Force Sarcoma Awareness to investigate and to define possible valuable approaches.

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SPAGN is the global network of Sarcoma Patient Advocacy Organizations:

Working together, making a difference.

Sarcoma Patient Advocacy Global Network (SPAGN) is the global network of national Sarcoma Patient Advocacy Organizations. In 2022, approx. 60 member groups from 5 continents gather under the umbrella of SPAGN, providing a common, international and influential patient voice for sarcoma patients around the globe. SPAGN is working to improve the treatment and care of sarcoma patients through information and support, and by increasing the visibility of sarcoma with policymakers and the public.

SPAGN was formed in 2009 as “Sarcoma Patients EuroNet (SPAEN)” to bring together sarcoma patient advocacy and support organizations from across Europe to give a unified voice to this rare cancer community, to share experience and to develop resources which can benefit sarcoma patients. The organization was opened to become international in 2016.

The SPAGN network consists of experienced, motivated and dedicated sarcoma patients and survivors, caregivers and patient advocates who want to contribute to improved care and management of sarcomas and who work to enable and support high quality research.

Board of Directors & Team

The SPAEN Board of Directors is a voluntary body of currently seven elected members who jointly run the organization with the support of an Executive Director, a small team of professionals (freelancers, part-time) and two elected financial auditors.

The current (elected) SPAGN Board of Directors:

- Markus Wartenberg, Chair – Germany
- Gerard van Oortmerssen, Co-Chair – Netherlands
- Kai Pilgermann – Germany
- Christina Baumgarten – Germany
- Vandana Gupta – India
- Sorrel Bickley – UK
- Denise Reinke – USA

The elected Board of Directors is currently supported by 5 appointed Board Members:

- Roger Wilson, Honorary President – UK
- Estelle Lecointe-Artzner, Honorary President – France
- Bernd Kasper, Medical Oncologist – Germany
- Ornella Gonzato – Italy
- Amy Bruno-Lindner – Austria

Team

- Kathrin Schuster, Executive Director
- Michaela Geissler, Director Projects & Events
- Cory Archibald, Director Communications
- Tanja Ullersberger, Accounting
- Herbert Thum, Design

Board of Directors:


MARKUS **WARTENBERG**, *Chair (DE)*


GERARD **VAN OORTMERSSEN**, *Chair (NL)*


KAI **PILGERMANN**, *Financial Director (DE)*


CHRISTINA **BAUMGARTEN**, *Board Member (DE)*


VANDANA **GUPTA**, *Board Member (IN)*


SORREL **BICKLEY**, *Board Member (UK)*


DENISE **REINKE**, *Board Member (USA)*

Appointed Board Members:


ROGER **WILSON**, *Honorary President (UK)*


ESTELLE **LECOINTE-ARTZNER**, *Honorary President (FR)*


PROF. BERND **KASPER**, *Board Member (DE)*


AMY **BRUNO-LINDNER**, *Board Member (A)*


ORNELLA **GONZATO**, *Board Member (IT)*

Team Members:


KATHRIN **SCHUSTER**, *Executive Director (DE)*


MICHAELA **GEISSLER**, *(DE)*


CORY **ARCHIBALD**, *(KWT)*

SPAGN’s Global

60 Member Groups fro

myrovlytis trust

The Liddy Shriver Sarcoma Initiative
a global initiative
for everyone affected by sarcomas

SARCOMA
STOWARZYSZENIE POMOCY CHORYM NA MIĘSAKI

swiss sarcoma
VON BETROFFENEN FÜR BETROFFENE

Sarcoma UK
The bone & soft tissue cancer charity

HENZO KENYA

gençbirder
Genç Birikim Derneği

Info Sarcomes
Ensemble contre les Sarcomes

GIST

gist cancer uk

opv
Associazione Orchestra per la vita ONLUS

AEAS
Asociación Española de Afectados por Sarcomas

SARKOME.DEUTSCHE SARKOM STIFTUNG

V Care
Coping with cancer - from chaos to control
Support and Hope for those touched by canc

SOS DESMOÏDE

Alianza GIST

CHORDOMA FOUNDATION

A.I.G.
Associazione Italiana GIST ONLUS

Sock it to Sarcoma!

sos desmoid

sarcoma alliance

Community 2023

m all Parts of the World

TRUST PAOLA GONZATO Rete Sarcoma ONLUS

Sarcoma SFA Foundation of America *finding the cure in our time*

TOGETHER FIGHTING SARCOMA

LeiomyoSarcoma SUPPORT & DIRECT RESEARCH FOUNDATION WISHING WORKING FOR THE CURE

synovial sarcoma research foundation

Sarcoma Cancer Ireland

Friends of Max

Together we share and learn

SMARCB1 e.V.

DESMOID FOUNDATION ASSOCIAZIONE ITALIANA TUMORE DESMOIDE ONLUS

DigiSwasthya

GIST SUPPORT ÖSTERREICH Verein zur Unterstützung von Betroffenen

BONE CANCER RESEARCH TRUST UNTIL THERE'S A CURE

SARCOMA COALITION We are here for you.

CUM CURA met zorg

Gyógyulj Velünk Egyesület

SARKOMFÖRENINGEN

CS CHONDROSARCOMA FOUNDATION

NLMSF National LeioMyoSarcoma Foundation

DTRF THE DESMOID TUMOR RESEARCH FOUNDATION

Sarkomer Støtteforening for alle berørt av sarkom

GIST.ch GIST-GRUPPE SCHWEIZ GROUPE GIST SUISSE

Patiëntenplatform Sarcomen

CAMPAIGNING FOR CANCER

gsi GIST Support International

The Life Raft GROUP

RARE CANCER 9EHE CHARITY (UK)

Fundación Mari Paz Jiménez Casado *Unidos frente al cáncer*

Suomen Syöpäpotilaat - Cancerpatienterna i Finland ry

GIST Organization

PAWS - GIST Paediatric Adolescent Wild-type GIST Syndromic Improving treatment & finding a cure for rare GIST cancer in young people

GIST & STS Alliance for patients - Bulgaria

MIB AGENTS MAKE IT BETTER FOR KIDS WITH OSTEOSARCOMA

ASARGA ASOCIACIÓN SARCOMAS DE GALICIA

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making a difference.

If you want to find out more about SPAGN, our objectives, initiatives and projects please visit our website www.sarcoma-patients.org or follow us on our social media channels:

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@sarcomapatients
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Sarcoma Patient Advocacy Global Network (SPAGN)

Sarcoma Patients Advocacy Global Network Association/e.V. (SPAGN)
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