



**Sarcoma
Patients
EuroNet**

**CODE OF PRACTICE between
Sarcoma Patients EuroNet e.V./Assoc. (SPAEN)
and the Healthcare Industry**

Sarcoma Patients EuroNet e.V./Assoc.

Administration-Office

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Founded: 6th of April 2009 in Bad Nauheim (under German law)
Registered: 11th of August 2009
Registered Association: Registry Friedberg/Germany VR 2609
Memberships: Full, Associate, Clinical Members
Memberships-fee: 20,-- EUR per member and year
Tax No.: 020 227 90219 (tax authorities Giessen/Germany)

Vision *A Better Future For Patients With A Rare Cancer!*

Practical focus Acting in partnership with experts, the healthcare industry and other stakeholders, SPAEN will work to improve treatment and care of sarcoma patients in Europe through improving information and support, and by increasing the visibility of sarcoma with policymakers and the public.

Objectives

- Increasing the awareness of sarcoma
- Providing information and support
- Improving treatment and care
- Supporting research
- Building capacity

Core Values

- Focussed on the needs of the PAGs (patient advocacy groups) and the patients/carer
- Willingness to advocate
- High quality of information/education/training: Correct, up to date, understandable, independent
- Cooperative and professional
- Ethical, transparent, behave with integrity
- Innovative spirit



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Many interests and stakeholders interact in our healthcare systems. Patient organizations have the role of ensuring that the patients' voice is heard at all levels of decision making, implementation and monitoring of policies and actions that concern health and healthcare and that the existing system achieves the best outcome for society. Patient organizations have a vital interest in interacting and communicating with stakeholders, including healthcare professionals, medical experts, regulators, scientists, industry, etc. - in the interest of their patients. Good communication will embrace trust, integrity, honesty and openness.

- The valuable and essential work of patient organizations and the service they provide needs to be recognised, valued and supported. However, most groups are struggling to find sufficient, diversified, resources, to fulfil their mission and objectives and remain independent, whether funding comes from corporate or public sources. Funding support for international activities is difficult to obtain. It very much depends on the organization raising its own financial resources and relying largely on volunteers to do the work.
- Credibility, transparency, independence and democracy are the most treasured assets of patient organizations. Every organization aims to be in a position to carry out its work based on the support of purely altruistic charitable contributions. However, there are only very few non-commercial sources prepared to fund patient organizations at a international level. This poses an ongoing challenge to all international patient organizations/networks/coalitions.
- There is a need to develop a strategy that will balance corporate funding with funding from other sources. We owe it to our future members and patients globally, who trust us, to act in a fully democratic, independent and transparent manner, according to the highest standards of good governance. We derive our legitimacy from our membership, our statutes and our democratically elected boards, many of whom are patients, caregivers or survivors who volunteer their time and expertise.
- Patients' organizations are keen to work in a constructive manner together with all stakeholders to ensure that the integrity of their organization is safeguarded.



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SPAEN's "Code of Practice" is as follows:

Sarcoma Patients EuroNet e.V./Assoc. (SPAEN) welcomes corporate donations, grants and sponsorship to fund certain projects and to enable the Association to grow and develop. This document outlines SPAEN's policy on commercial funding and provides a set of principles that will be used to guide SPAEN's decisions. It does not set out to provide a definition of every possible funding opportunity. This policy will apply to all potential relations with any company from any industry.

This policy is based on the

- IKCC International Kidney Cancer Coalition's "Code of Conduct"
- UK Breast Cancer Coalition's Policy Paper on Funding Arrangements with Commercial/Corporate Organizations
- EURORDIS's policy on corporate sponsorship,
- ECPC European Cancer Patient Coalition's policy,
- the recommendations of the UK's Long Term Medical Conditions Alliance.

A. Purpose of Policy

- To ensure that SPAEN has a consistent and transparent approach to working with commercial companies.
- To ensure the Association maintains its independence from commercial influences. SPAEN reserves the right to terminate any project or partnership where agreements have been transgressed or where the relationship contravenes SPAEN's "Code of Practice".
- To clarify SPAEN's position to patients, its member organizations, commercial companies and the wider public.
- To provide clear direction for SPAEN Board Members, enabling them to initiate relations with commercial companies with the full backing and endorsement from the members of the Association.
- SPAEN's Board Members are expected to adhere to the policy that will be reviewed annually and may be revised as circumstances demand.

B. Funding: Categories

There are different funding categories, including:

Project funding is where the Association will establish a collaborative partnership with a commercial company to undertake a project relating to an issue of mutual interest. The following features will apply to this relationship:

- SPAEN maintains editorial control over all materials produced in connection with the project
- The company will have representation on the project steering committee
- The sponsor's logo can be used - by negotiation with the company
- SPAEN will not endorse or promote the company or its individual products or services
- The wording and/or position of the credit will be agreed upon in negotiations with the company
- SPAEN and the commercial partners will both benefit from the relationship

Sponsorship is where a company funds a single activity such as a meeting or newsletter. In this case the following will apply:

- The company has no involvement in the activity for which the sponsorship is granted
- SPAEN maintains editorial control over all materials or meeting programmes
- SPAEN will not endorse or promote the sponsor or its individual products or services
- The sponsor's logo can be used – by negotiation with the company
- The wording and/or position of the credit are part of the sponsorship negotiations with the company
- SPAEN and the commercial partners will both benefit from the relationship



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Unrestricted grants are defined where all of the following apply:

- The company has no right to be involved in the project for which the grant is used
- The grant will be acknowledged
- The company's logo is not used
- The Association controls the wording and placement of the credit
- SPAEN will not endorse or promote the company or its individual products or services

Core funding: Funds for core activities should always be received on an unconditional basis. To avoid undue reliance on any particular company, such funds should be balanced and diversified as much as possible to avoid conflicts of interest and to guarantee independence.

Companies may offer financial donations and in-kind support to the Association however there is no obligation on the part of the Association to acknowledge the support, although SPAEN may decide to do so.

C. Sustaining Partnership

SPAEN "Sustaining Partners" are commercial companies that want to establish a long-term relationship with the Association and wish to demonstrate their commitment to sarcoma patients by helping SPAEN promote global understanding of the burden of sarcomas and the right of patients to effective early diagnosis detection, better treatment and supportive care.

A "Sustaining Partner" that donates a grant of 25,000 EUROS or more per year receives in that year:

- Recognition as a Sustaining Partner on the SPAEN Website and other communication materials of the Association.
- Direct link from and to the Websites. (This is only possible in negotiations with the company and in accordance to legal regulations.)
- Opportunity to meet the SPAEN leadership at an annual "Sustaining Partner Meeting" to discuss issues of concern to both commercial organizations and sarcoma patients.
- Opportunity to propose collaborative projects which will have priority status over those proposed by Non-Sustaining Partners.
- Regular e-mail updates on SPAEN's activities.



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D. Funding: Guiding Principles

SPAEN will foster dialogue, and establish collaborative partnerships, with companies/trusts/funds/charitable organizations whose commercial decisions affect the survival and quality of life of sarcoma patients.

Patient organization - pharmaceutical company partnerships are sometimes viewed with scepticism by decision-makers, the media and the general public. Some believe that pharmaceutical companies coerce patient organizations into conforming to their marketing agenda. In order to protect the Association's reputation and demonstrate that SPAEN does not conform to commercial agendas, SPAEN will adhere to the following principles when accepting project funding, core funding, sponsorship, grants or donations from commercial companies/trusts/ funds/charitable organizations:

- SPAEN will maintain an open, transparent and ethical relationship with all commercial and non-commercial partners.
- Where possible, SPAEN will solicit funding from consortia composed of two or more companies from the same industry (known as "multi-sponsoring").
- Before accepting funding the "Board of Directors" must be satisfied that there are strong grounds for believing the donation, grant or sponsorship will result in benefit to the Association and its members.
- SPAEN will closely review all potential commercial partners' corporate governance policies, their reputation in working with patient organizations and their environmental policies and practices. If there is any cause for concern, the Association will reject the funds.
- SPAEN will not endorse or promote a company or its individual products or services. The purpose of the Association is to inform their member organizations independently and not to promote or recommend special therapies, services, clinical trials or off-label use of therapies.
- A company's support will be acknowledged in an appropriate way following discussions with the company concerned.
- SPAEN commercial partners must agree to abide with the guidelines outlined in "Chapter E." below.
- If a company makes any attempt to coerce the Association to conform to its marketing agenda, either explicitly or implicitly, or does not conform to the agreement, SPAEN will reject the funds or terminate an on-going project.

E. Guidelines for Commercial Companies

The Association will not embark upon or continue with any sponsorship, grant making or collaborative venture that might damage its reputation or result in the dissemination of biased and inaccurate information to the general public and/or cancer patients. Therefore, when working with the Association, commercial companies should adhere to the following guidelines:

1. The Association must be consulted whenever and wherever its name is used, particularly in external communications. Approval must be sought for any copy produced which refers to an Association initiative supported by a commercial organization.
2. At no time can the SPAEN's logo be used without explicit written permission from the "Board of Directors".
3. At no time can press releases be issued which refer to the Association without prior approval of the "Board of Directors". Likewise suggested quotes can be prepared but must always be agreed by the Steering Group.
4. The Association retains a veto over all materials produced in connection with an initiative. Adequate approval time needs to be allowed for this as it may require approval from one or more Board Members.
5. All materials produced as part of an initiative of the Association will be in full compliance with the applicable legislation on information and advertising of medicinal products and will be impartial as to products discussed.
6. For all projects where the Association may be working in collaboration with a company and/or agency, clear lines of communication need to be established with agreement on respective responsibilities and assignments to ensure smooth progress with the project. The Association will have one point of contact identified within the company and/or company.
7. All correspondence with SPAEN should be directed to the elected "Board of Directors" not to individual members. The Board will delegate special responsibilities to individual Board members such as e.g . the management of relations with commercial companies.

F. Privacy Statement

- Individuals and organizations that are registered with SPAEN are entitled to expect that their information will be held in strictest confidence.
- No information about specific individuals or organizations is ever shared with, sold to, rented to, or made available in any way to any outside party without the specific prior approval of those entities.
- Internal access to such information is handled on a strict need-to-know basis under a signed confidentiality agreement with the SPAEN Board of Directors.

August 2010, SPAEN Board of Directors

President	Mr. Roger Wilson - Sarcoma UK
Vice President	Mrs. Estelle Lecointe - Infos Sarcomes (FR)
Vice President	Mrs. Christina Baumgarten - SOS Desmoid (DE)
Financial Director	Mr. Markus Wartenberg - Das Lebenshaus e.V. (DE)
Secretary	Mrs. Barbara Doré - GIST Support UK & GSI (USA) (Appointed by the Board.)