

Sarcoma Patients EuroNet

Together We Can Make A Difference For Those Affected By Sarcomas!



Deutsche Sarkomkonferenz / German Sarcoma Conference The annual meeting place of the German speaking Sarcoma Expert Community

The "German Sarcoma Conference" is an annual 3-day-conference in March for all German-speaking healthcare professionals and other experts interested in research and clinical management of sarcomas. Starting in 2011 – it has become the annual key conference for the German speaking Sarcoma community (Germany, Switzerland, Austria).

It was implemented by the German patient advocacy group for GIST and sarcoma patients "Das Lebenshaus e.V." together with leading sarcoma experts in 2011. The patient representatives felt that there was a major gap in transferring knowledge and experience in sarcoma research and clinical management in Germany. Many patients had been treated unprofessionally by non-experts and outside of Sarcoma Expert Centers.

The conference is an important block in the overall strategy of patients and experts to improve the situation for sarcoma patients in Germany. The general objective is to treat patients as early as possible in qualified Sarcoma Expert Centers. But also further to improve together topics such as clinical research, access, treatment quality, information and support, quality of life.

What is/are the target group/s?

The German Sarcoma conference aims to improve the interaction, networking and collaboration of all stakeholders in sarcomas in the German speaking countries. This includes healthcare professionals of all disciplines, centers, researchers, therapists, nurses, specialized networks, industry and patient representatives.

What is the timeline of the project?

The first conference was organized in March 2011 and was implemented since then every year in March in Berlin. Preparation starts in July with a "Program Committee Meeting" and with all organizational and logistical activities.

What resources did you need?

The conference is sponsored annually by 7 – 10 different pharmaceutical companies to cover the external costs. A detailed sponsor-partnership-concept offers different levels of engagement and services. Companies receive a number of free tickets to invite guests and employees.

But interested participants are also able to attend for a conference fee of 600,-- EUR (reduced 300,-- EUR). The budget of the 3-day conference to cover external costs is approx. 120.000 EUR + VAT. The work of all initiators and organizers is provided free of charge!

What results did you achieve?

The conference clearly became the annual meeting place for the German-speaking Sarcoma Community. Each year in March approx. 180 – 200 "sarcomologists" are coming together for this special conference in Berlin. It really supported us to give the sarcoma community a stronger voice – also in the political and in the research environment. In 2017 the German Cancer Society provided the community with the opportunity to start a certification process for Sarcoma Centers and to develop S3 national Guidelines. The conference was also a fantastic opportunity to integrate the patients voice much better into the expert community and to develop additional activities together.

Additional value of your project for the sarcoma population

Implementing the German Sarcoma Conference was the logical step to make sarcoma expertise more widespread among healthcare professionals who chose to be active in sarcoma management and care (ideally within sarcoma expert centers). The conference massively helped to increase awareness for sarcomas in the healthcare field and thus insuring that patients are referred more quickly to sarcoma experts and are treated to current standard of care including all novel findings. However, this platform needs to continue, spread knowledge and ultimately increase quality of care in sarcomas in Germany, Austria and Switzerland.





Das Lebenshaus e.V. Germany