Rare cancers represent more than 20% of all cancer cases diagnosed in the EU each year and affect more than 4 million people in the EU. Patients with rare cancers – such as Sarcomas, GIST and Desmoids - are faced with particular challenges, including late or incorrect diagnosis, difficulties finding clinical expertise and accessing appropriate treatments, difficulties carrying out clinical studies due to the small number of patients, possible lack of interest in developing new therapies, high uncertainty in clinical decision-making, and the scarcity of available registries and tissue banks.

Aiming to address those issues, Sarcoma Patients EuroNet Assoc. is actively involved as a partner in the Rare Cancers Europe (RCE) multi-stakeholder initiative. One of the main goals of RCE is to improve access to rare cancer care in the EU. The RCE partners have therefore jointly decided to do a survey in order to lay the foundation for the first-ever Rare Cancers EU Access Index, comparing different aspects of rare cancer care and policy in the EU. If you are based in one of the EU27 countries and are a member of one of the following communities, we would be very grateful if you could take 10-15 minutes to participate in this survey:

- Medical oncology
- Haematology
- Surgical oncology
- Radiotherapy
- Pathology
- Oncology nursing
- Patient advocacy
- Regulatory/National authority
- HTA (Health Technology Assessment)

To take the survey, please click on the following link:
https://sv.surveymonkey.com/s/rarecancers

The survey is conducted with the help of the Swedish Institute for Health Economics (IHE) and will be closed on 31 October 2012. All answers will be treated with confidentiality. The survey results will be disseminated through the RCE network of partners and used for information, education and advocacy purposes. As a survey contributor, you can also pre-register at the end of the survey to receive the final report, which is envisaged in December 2012. For more information on the RCE partnership initiative, please visit www.rarecancerseurope.org.