



Sarcoma
Patients
EuroNet



Sarcoma
Advocacy In Action
Award 2021



SPREADING AWARENESS AND BUILDING COMPANIONSHIP AMONG DESMOID TUMOR PATIENTS

Sachin Sarcoma Society started an initiative to spread awareness about desmoid tumors, building companionship and improving quality of life of patients by supporting them and working along with a team of medical health professionals.

Achievements

We started this initiative during the Covid 19 pandemic from our respective homes by hosting video calls on the Zoom platform for desmoid tumor patients and their caregivers. Based on the tremendous response and the positive impact that this initiative has made to the patients and their caregivers we have gradually increased on support and efforts on this initiative. We engaged services of a qualified Sarcoma nurse and have recently also appointed a psychologist to help counsel, educate and relieve anxiety, stress and depression in Desmoid tumor patients and their caregivers. Sachin Sarcoma Society has been helping various Sarcoma affected patients and their caregivers and have more than 3,500 patients within our span. Of these around 200 patients are suffering from Desmoid tumor.

These patients are generally from the lower income strata of the society.

How is this project innovative and special for the COVID situation?

India is a country with very high population and number of people who have limited means and education. When we started with this initiative during the Covid 19 pandemic we have various apprehensions as regards our ability of efficiently connect with patients and their caregivers given that they were from remote parts of the country. However, online platforms like Zoom, etc. really helped us in establishing connects with patients and through video calls wherever required we could establish emotional connects with these patients. Through our 24 x 7 helpline and various groups on Whatsapp we were able to connect patients with one another and they did really draw inspiration from the strength of each other and could also connect and exchange thoughts and experiences of their respective journeys.

Sachin Sarcoma Society

India