



**Sarcoma
Patients
EuroNet**



A Bridge for Desmoid Tumor

Physicians and patients share knowledge, fears, emotions and troubles to understand better the different point of view of this pathology”

Until the end of 2018, when we founded one, there was no Patient’s Association based in Italy and, for the people affected by this pathology, it was very challenging to retrieve and collect basic information, sometimes even to find hospitals organized and set up to treat this disease.

The Association has thus set itself the task of expanding the knowledge of each patient and acting as a bridge between the medical community and the patient community, with the aim of promoting correct information that can facilitate referral to more exact treatments and better coexistence with this type of tumor.

During our initial meeting, patient videos were recorded to witness the battle of each of them, to make known to our society the existence of this rare pathology, finally removing that “invisibility cloak” by which the Desmoid tumor has always been covered.

These videos will be published on Social Networks to finally give voice to Desmoid tumor patients.

The videos were filmed in Italian language and will all be subtitled in English because we believe that disclosure should be made on an international basis, as broad as possible. Even if patients live in different parts of the world, often our fears and doubts are the same.

Unfortunately, through these interviews it emerged that the knowledge level is even lower than one could have imagined.

We decided to collect patients' questions and asking directly the doctors, specialized in Desmoid tumor at an international level, to respond. Specialists working in Italy participated in these videos producing more than 50 video pills; each video focused on a different subject that clarifies possible doubts about the pathology.

The final audience will not only be the crowd of international patients, who will have the opportunity to receive correct and up-to-date information on their pathology, but also the doctors, who follow them during their therapies, and are not familiar with Desmoid tumor, as well as family members and caregivers.



**Desmoid Foundation Italy –
Associazione Italiana Tumore**