



**Sarcoma
Patients
EuroNet**

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



International Sarcoma Day in Spain. “Beyond sarcoma: people, words and projects with soul”

The title of the project is “Beyond sarcoma: people, words and projects with soul”, with the idea of bringing together patients with proven activity in social media (i.e. bloggers, most of them affected by Ewing sarcoma) and pediatric oncologists specialized in sarcoma. There were two discussion panels, one with patients moderated by a doctor and another one formed by doctors moderated by a patient.

The target groups of our activity were both, sarcoma patients and healthcare professionals familiar with sarcoma complexity. The public were mainly members of our association or former patients in general, interested in learning more about specific medical projects, in patients’ activism or simply who intend to talk and share their own fears with doctors or with people living a similar situation.

Although the act took place on July, coinciding with the International Sarcoma Day, our purpose is to give continuity to this first experience. And our second meeting, with the same format, will be on gynecological sarcomas (sarcomas affecting gynecological system). We assumed the challenge of regularly organizing a total of at least 3 seminars a year (the next one starting in 2019).

The central goal of this activity was to stimulate the exchange (at human and professional level) between patients committed in patient advocacy and doctors committed with patients beyond disease.

The result was extremely positive because of the feedback we have received and the possibility of increasing mutual knowledge. The only resources needed, so far, were merely technological, since most of the invited patients use online platforms for their projects.

With regard to long-term objectives is too soon to evaluate them. But the immediate result was a successful rating in social media. We estimate that a regular organization of a workshop like this will help, not only to activate the participation of more patients, but also a greater visibility and outreach of the sarcoma patients and their everyday life.

Additional value of your project for the sarcoma population

The project “Beyond sarcoma” intends to show the online activity of patients that make an effort to render sarcoma more visible, and on the other hand it brings them together with doctors specialized in sarcoma. We can affirm that it had a big impact in the entire population of patients of sarcoma in Spain, for whom this act, the first one celebrated in our country, became a reference for all of them.

JORNADA MUNDIAL DEL SARCOMA EN ESPAÑA “Más allá del sarcoma: personas, palabras y proyectos con alma”

Barcelona, 9 de julio de 2018
de las 16h a las 20h de la tarde



Melissa Carroll, *Limbo* 2013. Acuarela
https://www.huffingtonpost.com/daniel-maidman/recurrence-melissa-carroll_b_3776475.html

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Asociación
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