

Accessing Clinical Trials from patient perspective



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Who am I:



Happy husband



Digital Expert



Hiker

My story and how I found out about melanoma

“Everything happened with two weeks before I go in my honeymoon”



“A surgery to remove the mole; initial I thought this will be a laser intervention”

“A routine check on my dermatologist”



“Melanoma diagnostic was presented to me with two days before I was supposed to leave in my honeymoon to a country with beautiful beaches”

The first steps in the story

Encountered problems

- I did not know what steps to follow for investigations. In Romania we do not have a central system that allows direct collaboration between dermatologist, surgeon and oncologist
- Not all oncologists were on hand (up to date) with the latest therapies
- The only option available in Romania for melanoma stage III was interferon and lymph node dissection

Investigations and their duration

- A quick time finding your stage is a great deal, here's how long the investigations took for me
- Melanoma discovery, removal and histopathological outcome: two weeks
- Identification of the sentinel ganglion lasting one week
- Removal of sentinel ganglion at 36 days after initial diagnosis of melanoma, their analysis (immunohistochemistry): two weeks

Melanoma Romania Association

- From the information I received from a US doctor I learned about immunotherapy (Nivulomab and Ipilimumab); unfortunately, these treatments were not approved in Romania for Stage III, resectable
- A Facebook search has done wonders, so I learned about the Melanoma Romania Association; they informed us about existing clinical trials in our country
- Finding the group was opportune because we had the chance to get to know Violeta [Astratinei](#) who led me to the clinical trial that was enrolling at that time

What does the Clinical Study mean to me and what prompted me to access the study

1. Accessing new treatments with proven good results!

2. US guides helped me make the decision to access the program faster

3. I had an open discussion with Dr. Schenker before enrolling in this study

4. On my first visit to Craiova, Dr. Schenker and Dr Alexandra Dumitrescu have explained me what happens in this study and what treatment I can access

5. I have waited around three weeks for an answer if I can join the study or not, which it seemed a lot to me

6. I knew this study was my chance to access a innovative therapy!

My life as a patient enrolled in the study



- You need to plan the trip for taking treatment if the clinic is outside your city. I visited the Oncology Center "Sf. Nectarie "in Craiova once every two weeks (230 km)
- I greatly appreciate the doctors and nurses from the center for their dedication and the very good services they offer. The services provided made me confident I took the right decision
- Nurses are prepared to cope with any situation even if "you did not bring your veins with you" they find one! 😊
- The doctor is always interested in my health and asks me for side effects, we use technology like WhatsApp to communicate and report these
- I get advises on how to better protect my self; I try to keep away from the sun as much as I can, I wear always a hat and use sunscreen cream 50+
- I have to schedule my time better depending on the treatment. Life, treatment, work, family all need to be in balance
- I can say I have a normal but better organized life!



I would advise newly diagnosed patients to talk with oncologists about new therapies. To join the Melanoma Romania Group to be up-to-date with the latest approved therapies and if there are new clinical trials to access them. Melanom Romania Group has dedicated, and well-trained volunteers doing a great job in always keeping us informed and presenting the latest news in the field and that's why I would always be grateful to them.

Our association a powerful voice

What we expect for the melanoma patients

A longer and better life!

What we want for melanoma patients in the context of CTs

More Patient Centred Clinical trials with Innovative Molecules in our Own Country!

What we need

More info and transparency on clinical trials in general! More info on protocol and dosing for example in my study did not have specified doses and people have learned from consent form, so after the decision was already made.

What's next for me?

Before the treatment started, we received a good advice from the doctor, results are in the images



Fertility and pregnancy is affected by cancer treatments, so these aspects should be discussed with all those starting a family or without children!

Thanks to the fact I was well, I have now a normal family life with my wife and my one year old son!



**My wife and I are
very happy for this
little wonder**



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O ASOCIAȚIE PENTRU PACIENȚI

Thank you!

For any questions please write to our addresses below:

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