

## Patient disease perspective

To start from the beginning, we would have to go back to the end of 2012 when I noticed a lump in my left leg. After several visits to the Primary Health Center and the Hospital's Emergency Room, I was prescribed ice and anti-inflammatory medication. Finally, I was referred to the orthopedist at the Specialty Center, and after asking for an MRI I was referred to the Hospital's Emergency Room, where I was told the probable diagnosis of my disease.

From the diagnosis, everything went very quickly and in February 2013 I had my first operation to remove the tumor and the surrounding area to ensure a sufficient margin. After recovering from the operation, I had several sessions of radiation therapy with immobilization devices, which ensured tumor wouldn't relapse in the radiated area, but unfortunately, I also had a lot of deterioration in the adjacent normal tissue. These sequels are the most important ones I have, since they cause me a muscular deterioration, and muscular fibrosis along with a chronic venous insufficiency and a chronic neuropathic pain, which limit my daily life.

Over the next few years I had four relapses in different areas of my legs, which were detected by myself when I noticed lumps of the same characteristics as the initial tumor. All of them were managed with surgery and different treatments before, during and after the operations, with less aggressive side effects. Probably due to not using a cast or to being areas with more muscle mass. Preoperative radiotherapy produced a reduction in the tumor in one of the operations, which also meant that it was not necessary to remove such a large safety margin. These operations have also caused me loss of muscular mass in both legs, which, together with the initial operation, limit my movements and require me to lie down for part of the day.

I have also undergone right lung surgery due to the appearance of several nodules, which in the end were reported as benign lesions. However, I currently have metastases in my lungs with new nodules, which is confusing for me.

The last surgery was due to a gastric relapse and after months of slow recovery, I have now hardly any sequelae.

After the following 3 cycles with the new treatment, I

have been told that the disease is stable (it has not grown, but neither has it diminished) and I am going to continue with another 3 cycles before the next revision.

In summary, after 8 years with the disease:

- ❖ I think there is a lack of screening tests to detect this type of tumor earlier or in very early stages for the first time.
- ❖ Once you are already suffering from it, I believe it is difficult to control its expansion, since the imaging tests for controlling the disease are carried out mainly on the affected areas. In my case, I had recurrences in areas close to the areas that were being followed-up, but they were not detected since the MRIs did not include such new areas.
- ❖ My type of cancer is rare or infrequent, so its behavior is not very predictive. I think this is due to the lack of research or information on similar cases.
- ❖ Regarding the lack of information about my type of cancer, I believe that chemotherapy does not have specifically targeted drugs, since after different types of chemotherapy, it is not having the expected effect on me.
- ❖ On the other hand, I am very satisfied with the proactive response of all the hospital staff, with a rapid response to the initial diagnosis and the subsequent relapses, the quality of the different surgeries and treatments available so far.
- ❖ I would also like to highlight the humane treatment and the accessibility when needing any consultation.
- ❖ Physically, I have a 35% disability and soon I will have a permanent total disability. The consequences of the surgical and adjuvant treatments allow me to live a normal sedentary life with certain mobility limitations.
- ❖ My attitude, despite receiving bad news after bad news over the years, has always been very positive. Nowadays, being at stage IV and the fact that the disease has spread to other parts of the body, lead to pessimistic thoughts about whether I will be able to recover from it. However, there is no other choice than to move forward with positive attitude and follow the advice and treatments of professionals to fight and defeat this disease.