

Hello

My name is Brianda, but everybody calls me Bri. I don't really know how to start so I am going to tell you how I've felt ever since I can remember.

Ever since I can remember I see myself in a hospital, although it hasn't always been that way and, broadly speaking, I've had a normal life, yet always influenced by my disease (HP).

My mum says that, as a baby, I used to cry a lot and, when I was three years old my mum took me to the paediatrician – who said there was nothing wrong- and she said: “Even if there is nothing wrong we need to go to the hospital because that cry is caused by pain”. And it was at that point that everything began: I was hospitalized due to urinary tract infection, ultrasound scans, genetic tests... My first memories are made of doctors and more doctors. At first, I didn't completely understand what was going on, I just knew that I was sick and that I had to see a doctor. I also remember when I began taking medication: there was a syrup that supposedly tasted like orange but it tasted very bad. I also took vitamin B6, which didn't taste good. Other memories about the medication include the feeling of my throat and mouth burning and stomachs so I was prescribed a stomach protector, which didn't work and caused me headaches. From there, I continued to pills, also for my blood pressure.

Besides the medication, I have many memories being at Emergencies because of nephritic colics, hospital stays, arguments with doctors. I missed school very often and spent days in bed. I felt I was an alien, different from other children: I was on strict diets, I couldn't stay at a friend's house because of my medication and many days I had to leave school because I didn't feel well.

My life continued the same way until last year (2018): I was given some news which, at first, was great but that gradually changed.... Mabel told us we would participate in the Oxthera clinical trial in october-november. I started going to Barcelona quite often, I would also hear my classmates say “Poor you, get better”. That made me feel worse than I actually felt. The 14th February 2019 was one of the worst days in my life, when I started taking Oxabath or, as we call it at home, “the bugs”. Everything started a week later: nausea, low blood pressure, dizziness, stomach aches, anaemia. Two weeks after starting the treatment I went back to hospital. Over time I felt worse and worse, it wasn't just the HP but also emotionally so I sometimes can't see the point in following the treatment because, to be honest, I am now worse than a year ago. I don't want to sound like I am not grateful, quite the opposite. I'm very grateful for everyone's support but well, that's how I feel. Once I have told the story of my life I would like to thank my mum for understanding my mood swings and always travelling to Barcelona with me. To Miki, for his moral support and to Ana, for standing by us. .

1) What does the pain feel like?

I know when the pain is going to come because I feel uncomfortable. The pain starts near my right kidney and it feels like a stretch. Then comes a kind of blow and the pain moves up and down. It gets to my buttocks and I gradually stop feeling my leg (my left side hurts too) and I slowly feel as if I was about to pass out because the pain is very intense and it is like I fell asleep. Once I get a shot the pain gets milder.

2) Anxiety.

Ever since I can remember I suffer from anxiety and, usually, colics come with an anxiety attack , though I have also had anxiety attacks for no reason, just thinking about my disease or going to the doctor makes me feel this way, scared in case I get some bad news or I am told none of this is working. All of this make me feel really bad.