

HELLO I'M

Tatiana

I am 48 years old and I am a Brazilian citizen.

I've been dealing with TN over the past 15 years. The first shock I felt I was in my house and I felt a strong shock in my cheek in the right side. I thought it may be something wrong in my tooth and I booked an appointment with my dentist. She didn't know about TN and so she just said nothing was wrong with tooth. The shocks started getting stronger and I went back to the dentist and asked her to extract one tooth, but of course it didn't work.

It took 18 months for me to finally find out what exactly mean those horrible shocks and that excruciating pain I was feeling several times every day.

When I was bad I went to ER and believe me, nobody was able to tell me what was happening.

Brazil unfortunately has a very poor knowledge about Trigeminal Neuralgia and the treatments and surgeries are badly conducted because there is no any research in this country.

I found out what was leaving me crazy, believe me, after 4 hours researching on internet. I found an interview of a neurosurgeon from São Paulo where I live and then I booked an appointment with him. As it happens with everybody, I started with Amitriptyline and Carbamazepine, increasing more and more without any result. Then I had 4 procedures with balloon and 4 radiofrequency, with Lyrica, Gabapentin, Phenytoin, Lamictal, Baclofen, Clonazepam. I also tried Oxcarbazepine, but the doctor had to interrupt it because I had the beginning of Steven Johnson Syndrome.

I also had two MVD surgeries, without any success, the second one the doctor was supposed to cut completely the Trigeminal nerve, but he just cut a small part what resulted in a serious side effect like the complete loss of the sensibility on the right side of my face and my head, a terrible problem in my right eye, compromising deeply the vision of this eye, my mouth got a little asymmetric and the pain and shocks still strong.

I used three different CBD with THC but not with a great success. Now I am waiting for a new one to arrive to try once more.

Today I am a TN fighter on the three branches on the right side.

The way I decided to guide myself was begin a huge battle to bring awareness to this country. I created a channel on YouTube, my Instagram, I created a couple of mascots just to show awareness in Brazil. I made a legal registration of them to avoid problems and I never give up! I am a Support Group Leader Volunteer of the Facial Pain Association for Brazil and Portugal and every year I create some new products to sell and send the money to FPA to the researchers.

The fight is really huge, but I will never give up!