

My SPS Story  
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Since Golnaz does not speak English as her native language I have done some editing for her by request. Sam Baar

You cannot imagine how much I was excited finding someone like me on the other side of the world. I am 42 now, and been diagnosed with SPS for 3 years, while facing the problem since 35.

I was sky player, used to start Tennis. I had an 11 years old son. Giving him all possible services a mother can give her child. Even the time I was afraid of walking and his father was absent, I still was getting him to school and supporting him with different activities.

I was treated by a psychiatrist as a depressed person but fortunately he was giving me the right medicines i.e. baclofen and diazepam and another anti anxiety medication.

My problem is a somewhat different than others. That is, I don't have any diabetic disease, but Thyroid issues.

You never faced jerking! Or you did? I've been admitted to hospital in second year of my SPS because of worse spasm which causes jerking. A very famous neurologist there told my parents he had never seen such disease in the whole 40 years of his professional life. He then said because of the stiffness, I am losing my liver and kidneys. Then he admitted me in ICU, and started to give me morphine. I was there for about three or four days but I just can remember only a few hours of it.

Then my husband who was abroad (in India) studying psychology came back, and he came to the hospital directly from the airport. I'm quite sure that my problem gets worse whenever I face tension, as that morning, before he came, and I was in good mood (still in ICU) my sis told me that he was coming. That day was my 37th BD, and I believe it was the best gift I'd ever had, but it gave me a big shock. Again jerking started, together with more stiffness and pain (you know).

After I met him, tears were covering my whole face and I was asking him not to cry. But the day after, I begged the doctors to give me permission to stay in the private room as I was sure the best nurse would be my husband. After a long discussion between my father and head nurse, she accepted.

I was there, for more than 14-15 days. The neurologist said that it was a virus and now it has left the body!!!!

Yet I was unable to sit, because of back spasms. During the next month they were hospitalizing me, putting bed-pan, giving me bath only in a bath tub with warm water and physiotherapy at home.

I was (and still am) a very active woman, handling a big market of lubricant in the whole country. So it was really difficult to believe this would be the thing I should adapt it.

Then, after a serious phase of my problem I again asked my psychiatrist to visit me at my home. He again said that your problem is anxiety only and you should start taking related treatments again.

I accepted

Then my husband after 3 months staying with me went to India to continue his education. This time I was much better. Even there was no more need for a hospital bed which we had got from a friend.

After three months my son and I joined him. I started Yoga treatment. It was really the best decision in my life to move to India, and doing Yoga.

After few months I decreased my medicines, down to zero. And after 11 months from the time I stopped taking medicine, I got pregnant again and now I have a very cute, green eyed Indian son :) Albeit only after three months from delivering, the SPS started to show itself again. I really was worried to whom I should go to this time, because I could not trust doctors anymore. I asked my Yoga guru, to treat me at home. But after a few sessions they said they would continue only if I accept to go to a physician. I asked my husband to get an appointment from a psychiatrist he knew very well, this time I was bleeding worse than usual bleeding after I stopped breast feeding. It was more than a month I was bleeding. That time because we were alone, I hired an Indian lady to take care of me and my son. So I thank God that I had her.

Anyway, we hired an ambulance, with stretcher I went to doctors for both problems. Psychiatrist said I would give you medicine but you should meet with a neurologist. He introduced me to the best he knew. He came and after a few questions and a physical exam he diagnosed SPS. I was crying, being happy some one knew what this is.

After GAD65 test, he said now he is sure about the disease. The number was above 1000.

So he started to give me 25 injection of something like what you call IVIG, only for 5 days. On the third day I was able to raise my leg and put it on the other one. It was a miracle for all of us.

It was the only time I got treated with IVIG.

Then after getting better let's say after a month I again started Yoga at my place, together with doctor treatment.

The problem of mine is that with every tension I become stiff. And it would take time to get rid of it.

Sometime back I had a big tension and I felt that it was coming. So I called my doctor and asked him for anti anxiety medication. He suggests starting Clonazepam 0.5 morning and evening. Now I was feeling better.

I was hoping to get rid of this disease. I believe it is completely related to my mentality.

Now Yoga, some sort of medicines such as Baclofen, Diazepam, Mycept, and Clonazepam are working together.

I never mentioned I'm Iranian, am running a company in India going for horse riding and feeling much better than 3 years back.

I continued to study after being diagnosed with SPS, I received my MBA IT and now I'm going to get my PhD.

I'm running my business in a very good condition, and all of this was after I got my disease.

Cheers Golnaz