

ANLICHE
Nominee written article

April 30th, 2021

Dear Golden Light Awards Committee,

I would like to tell you how I got to where I am now...

When I was a child, I had a rare kind of epilepsy, with an abnormal electroencephalogram and I used to have seizures very often, sometimes many in the same day. It started when I was around 6 years old. I remember going very often to the neurologist, having to take different tests, taking tons of different medications, feeling sleepy, and not being able to go to school. At the beginning I had so many seizures that I needed to wear a helmet to protect my head, and I hated it because it made me feel different. I also remember how frustrating was not being able to do the same things that my peers did, for example once I started attending to school again, I couldn't go to swimming lessons because it was not safe for me. After a couple of years, trying different combinations of medications, reviewing all possible treatment approaches (which even included going abroad) and with the support of my family and my neurologist, I started to have less seizures until the point I did not have seizures at all. It was a long process in which I could slowly come back to school and started having a more normal routine with less medical appointments and more social activities. Fortunately, my epilepsy did not affect my cognitive nor my motor development, and I managed to be the first in my class during secondary school and to make some very good friends. By the time I turned 18, I was without medications and seizure free (which was kind of a miracle considering the nature of my epilepsy).

The experience during my childhood paved my path towards becoming a professional who could help children with motor problems due to neurological causes— a physiotherapist. I have been working as a neuro pediatric physiotherapist for more than 7 years and I am really passionate about it. It is very fulfilling to help children and adolescents to improve their skills and quality of life. Every patient, every child needs a different approach, different exercises and different techniques. Notwithstanding the fact that I have taken several courses about neurorehabilitation, I wanted to keep learning and developing my career, so I studied a master's degree in Clinical Neuroscience at University College London. I got distinction which makes me feel very proud considering that it was a challenge to achieve in such a prestigious University during the pandemic situation.

I have always felt very grateful for all the support that I received from the Chilean League against Epilepsy during the years that I was unwell. To try to contribute back, in 2019 I created and coordinated a physiotherapy voluntary project at the Chilean League against Epilepsy. It helps to improve the quality of life of children with motor impairments due to epilepsy. Last year the project was in a pause because of the pandemic situation, but my plan is to continue with this voluntary Program and to expand it so it can also include speech language therapists. In addition, I would like to support the interaction between the Chilean Chapter and the IBE, contributing as appropriate to the international best practice exchange, for example helping with translations when needed. Moreover, I applied for the new Global Academy Team from the IBE, and I am really looking forward to know if I am going to be selected to participate. I am keen to keep contributing to the Chilean League Against Epilepsy, and to start to participate in the IBE in order to help and empower others with epilepsy so they can overcome their obstacles and achieve their dreams.

Yours sincerely,

Valentina Kahn Santoro