

María Elvira García Ronderos

I am the mother of a 27-year-old young PWS. I am currently the President of the Colombian Association of Prader Willi Syndrome. I feel very happy and grateful to have the support that IPSWO has given us, thanks to them we were able to successfully carry out the First SPW International Symposium in Bogotá, Colombia in March 2019. For that opportunity we had the accompaniment of Linda Gourash (medical pediatrician) and Amalia Balart (Member Board for Latin America).

Then, the IPSWO helped me with a scholarship to attend the 10<sup>th</sup> SPW International Congress in Havana, Cuba 2019. It was a great experience, I met exceptional people dedicated to helping us to investigate and learn more about the syndrome. I met parents from all corners of the world with different cultures and languages but all united around the desire to learn the best way to help out children.

I was accompanied by my husband and Dr. Carolina Cárdenas, Director of the Medical Committee of the Association and Neuropsychologist profession.

In the conferences addressed to Caregivers, we receive training that we will use to train people in Colombia to help us take care of our children and to develop a long-term project of houses where they can provide adequate care and spaces for them; It was motivating to see how they do it in Europe, Australia and the United States. It is a challenge to be able to do something like that in Latin America.

Regarding to clinical and scientific conferences, we find encouraging advances in treatments for hyperphagia, anxiety, forms of orthopedic care, growth hormone management, among others.

In the conferences for parents we find many answers to the behaviors of our adult son, and training in the care of children and adolescents. We will share the knowledge learned through our YouTube channel, ACSPW. There we have a monthly meeting with this type of speeches, and we already confirm some of the speakers invited by the IPSWO to be part of our YouTube speakers.

With the information translated into Spanish that the IPSWO provided us, we will develop parents' workshops to discuss the material and contribute with our experiences to its implementation.

The most important thing this conference left me with is the confidence that I can now be a better mom for Carlitos and I feel more prepared to help our Colombian and Latin American families through our Association.