

Attending the International Prader-Willi Syndrome Organisation Conference was an experience that changed my vision in regard to the needs of people living with Prader-Willi syndrome.

My first contact with this health condition, outside of a genetics textbook, was in June 2009 when I met Lupita in Mexico City, a couple of months before starting my yearlong physical therapy internship. In December of 2010, I started working at a Mexican rehabilitation center for children called Fundación Teletón México AC. More specifically, I was working at the branch located in the northeastern Mexican state of Tamaulipas, where I had the opportunity to offer my services in physical and respiratory therapy to children with different genetic syndromes, including a few with PWS.

Time passed, and in 2018, Lupita's family contacted me to see if I was interested in giving a talk about physical therapy for parents of people with PWS to which I responded with an effusive yes. This was an opportunity to collaborate with Fundación María José and IPWSO. An occurrence that, at the time, went unnoticed. Later, it came to be that this unexpected happening was what gave me one of the most enriching, professional and personal experiences; I received a scholarship to go to the 10th annual IPWSO conference in Havana, Cuba.

I attended this conference with the goal of acquiring more efficient tools and strategies to help treat the syndrome. I also hoped to learn more about the syndrome from people who were highly trained in the subject, so that I could eventually create physical therapy programs for people living with PWS in Mexico.

However, I received much more than I expected.

Each of the talks in the program for professional providers and caregivers gave me important details as to how I could improve the societal participation and inclusion of people living with PWS. The event that stood out to me the most was the one where the Danish team's video, "Supporting Health Situations in Fejo, Denmark", was shown. They, with a lot of support from their government, have created a safe and inclusive space in a community where the residents of this group home are able live their fullest lives. From this video, the lesson that I will cherish forever is to "remember to listen, remember to talk to each other and remember it's ok to ask for help" because I believe it teaches us a philosophy essential to living a life worth living.

Regarding the location, it seemed to me that having this event in Havana opened the opportunity for many Latin Americans to attend, and, above all, to allow for more diverse networking opportunities for those who are in some way a part of the Prader-Willi community.

Thanks to IPWSO and this incredible opportunity I received from them, and to Tony Holland's presentations on legal basics and ethics, as well as Elizabeth Roof's motivational and inspirational talk on early education, and the extracurricular talks I had with great people like Linda Gourash (USA), Lynn Garrick (USA), Georgina Loughnan (AUS), Giorgio Fornasier (ITA), Karin Birkedal (DEN), Trine Jensen (DEN) and Christina Brydegaard (DEN), I will propose the following objectives to the members of the María José Foundation Committee in Mexico:

- Improve the care, quality of life and societal inclusion of people living with Prader-Willi syndrome by better detecting the specific needs of these people and their families.

- Identify these needs by conducting face-to-face as well as virtual workshops
- Train parents to prevent the development of skeletal muscle sequelae which form as a result of muscle weakness and hypotonia that occurs in the first years of life.

Thank you friends of IPWSO for this opportunity.

Sincerely,

Juan Carlos Reyna Mayorga
Physical Therapist
Mexico