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Opinion

Do You Know Dravet Syndrome? A Disease that Impacts Families Seeking Life Expectancy

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My name is Nohora Ramírez, I am a psychologist graduated from the Catholic University of Colombia. Professional experience of more than 14 years in the Organizational and clinical work areas. Currently Founder of Dravet Colombia.

My main work is focused on the work that I carry out in functional neurorehabilitation to patients who suffer from the same disease as my 6-year-old daughter Luciana, who is a carrier of Dravet Syndrome. We share our story on social networks and on the YouTube channel: www.youtube.com/c/NohoraRamirez1234.

It is a myoclonic epileptic encephalopathy of early childhood, a disease of genetic origin with low prevalence 1 - 20,000 births, which appear the first of life, drug resistant to clinical treatments, with multiple changes in the types of seizures they suffer and a risk of sudden death, the disease is neurodegenerative, with progression to encephalopathy, delay in the development of moderate to severe. Currently Dravet Colombia, like the functions created worldwide, is up to date in the knowledge of gene therapies with biotechnology companies that develop oligonucleotides or adeno-associated vectors for the cure of the disease.

From our personal work, the impact is to accompany not only the patient, but also the family, it is a difficult process of acceptance of the disease, since it is the first step to articulate a better treatment between the medical team of specialists of type of diseases of high complexity, patient, and caregiver to provide improvements in patient quality.

When this first step of acceptance is achieved, all the factors involved, we are oriented to the rehabilitation of patients accompanying and supporting regular therapists who allow to level the areas of neurodevelopment, in our case it is a little more specialized, we seek to reposition the functions and the loss of children's abilities through training in playful play, acceptance of activities and behavioral patterns.

Working in this area has allowed me to share experiences with different families at a global level, to have active collaboration with other professionals in the area of health and education in my country, Latin America, Central America, the United States, Europe and some Arab countries.

And also share with other foundations that are dedicated to raising awareness of the disease since we all dream of the day that very soon, we will have a cure from gene therapies and we can say that our carriers have "a world without Dravet syndrome.

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