

**SOUTH AMERICA
CONGENITAL
HIPERINSULINISM
CONFERENCE**

NOvember 2016

My name is Paz, I come from Paraguay and I want to tell you why I'm here.

In 2011 my youngest son was born with Congenital Hyperinsulinism. Even though we were in Intensive Care for 3 days right after he was born we didn't know he had something until three months later when he started having these rare symptoms.

No one knew what to do, no one knew how to help us, We had to take him to 3 different countries to finally find the right diagnosis, the right treatment and finally be able to go to a 4th country to get the surgery done, it is good to know that we were wrongly diagnosed in two of those countries.

We were very lucky, we had the money and the time to go through all this, but... 4 countries!!!!

My child was cured, but after all we went through I said to myself "I can't let this happen to any other children! it is too dangerous and too risky! my son could have ended really bad!"

But... we have to deal with the reality of countries like mine, and that is that we do not have protocols, we do not have enough specialists, we do not have enough expertise, we do not have the right equipment, we do not have enough information, we do not have enough support, we do not have a data base, we do not have the money, we sometimes do not have the medicine, we do not have so many things, and so guess what?... here is the answer of why I'm here...

I am here because I believe with your help we can change all this "we do not have" for "WE DO HAVE"

The purpose of this conference is to give children from South America the possibility of a normal life.

How? I hope, giving the South American doctors tools to handle the situation as best as possible considering the resources they have, creating awareness, sharing information, investigation, progress and experiences, creating a networking so children with Congenital Hyperinsulinism will be diagnose on time, will be able to get treatment on time, will stop dying and getting brain damage for no reason.

Why Paraguay as a location?



Because it is right on the center of South America, making it easier for everyone to come together in this one Conference that will be for the benefit of all.

We want to gather for the first time endocrinologist, pediatrician, neonatologist, surgeon, neurologist, congenital errors, metabolic and every other specialty from every country in a South America Congenital Hyperinsulinism Conference where they can all take advantage of the knowledge of the speakers who will join us there. Luckily that will be some of the great Doctors that are here today.

In this Conference we are looking for improving the procedures to diagnose, treat and doing surgery when needed, considering the resources each Country has for it.

Some countries in South America are more developed but some others like Paraguay really need help getting the basic things doctors, hospitals and families need to be able to deal with a patient with Congenital Hyperinsulinism.

Working regionally will help a lot in many cases, one of them just to give an example is getting medications in every country, it is something that individually we can't do it.

I want you to know that after what I went through I can't just walk away with my cure child just doing blind walk through life knowing that other children may not have the same luck we did.

I want to help them and their families to find the way to go out the hard time it means to have
Congenital Hyperinsulinism

I want to help preserving the quality of life of many children no matter their economic situation.

I just can't do it by my self, so I really want to thank Julie Raskin, for giving me all her confidence and support for doing this, and also I want to thanks CHI and the people who belong and work for it for all you do and for giving me this opportunity to make this dream became true.

Thank you all for sharing what you have and for giving your time and interest for helping others.

Thank you and God Bless you