

2004 MSUD SYMPOSIUM - ATLANTA GA

The symposium began at 1:00 PM. I struggled to understand what was going on and would occasionally pick up a word here and there. Thank God, Melinda was able to join us for a few hours. But when she had to leave, the speaker was in the middle of a lecture about nutrition. Soraya and I became like blind people. We were completely lost.

Once again, we were very blessed. At the end of the day, Joyce introduced us to an Argentine who worked for a computer company in the United States. Eduardo Gatica was the father of a MSUD child born in his home country. Fortunately, I could understand my new South American friend very well. The only thing we could not talk about was soccer, because soccer is almost like a religion in South America and should not be discussed, especially between Brazilians and Argentines if you are to remain friends.

On this basis, my friendship with Eduardo began. He told me his story about his daughter's MSUD and coming to the symposium on his own. Like us, he faced the same difficulty to properly and quickly screen the amino acids levels. It turned out that in Argentina, just like Brazil, MSUD was not common and they didn't know how to deal with it. His daughter's case was so similar to Artur's except for one aspect. His daughter was diagnosed earlier than Artur and this makes a huge difference.

Mrs. Joyce joined Eduardo's and my conversation and told us a story about a case of MSUD in Brazil that reminded me of Yslani, the little Brazilian girl who died. Consequently, her story hit me like the sequel to a bad movie. With permission from the family, Mrs. Joyce published this story on the MSUD Support-Group website.

Joyce Brubacher – Editor

"I received a fax from Brazil on March 7 of this year. The urgent message was from Joao Carlos de Oliveira Mello, the father of a recently diagnosed infant with MSUD. His son, one month old, was undergoing dialysis in intensive care. He read on our Web site about TPN (Total Parenteral Nutrition) for MSUD, an IV solution available without leucine, isoleucine and valine that provides total nutrition via IV. It is now the recommended treatment for quickly lowering the branched chain amino acids (BCAAs). The baby was drinking the MSUD formula from Mead Johnson, but he wanted the TPN, which is more effective in reducing the high levels of the BCAAs. He wanted to know how to get it from the States as quickly as possible".

"Joao and I continued communicating by email. I sent information so his doctor could contact other experienced doctors both in the States and in Brazil. I also sent the information about where to get the BCAA-free TPN. On the 8th, Joao reported the baby was doing better each day. They were praying that their baby would soon be in good health again. They had followed instructions to get the IV solution".

"Two weeks later, I realized I had not heard from him since the 8th. I sent an email asking how the baby was doing. His reply shocked us. The baby had died the week before. Joao said his son had died of complications from the MSUD. The MSUD TPN solution arrived too late because, as Joao says, "The customs and bureaucracy here is unbelievable."

"How very, very sad. Joao and his wife were married 12 years and this was their first child. Although the family had available resources to transfer the child to the U.S. for treatment, the health of the baby was too poor to permit transport".

"I asked Joao if I could tell about their experience in order to expose the plight of families in Brazil and other countries. He mentioned some of the medical problems they faced in Brazil. Only one laboratory in the country could provide BCAA levels in a short enough time to be useful for monitoring. And this was at a university far from their city. The medical food (formula) and TPN solutions have to be imported. In their situation, these were delayed in customs, and an extra charge of 88% was applied for the TPN (which is already very expensive)"...

http://www.msud-support.org/index.php?option=com_content&view=article&id=196:Sharing---All-is-not-well-in-Brazil-&-in-other-countries&catid=31:volume-18-1&Itemid=5

The only difference between Joyce's sad story and mine was that my Artur did not die...