

GRUPO APOYO VICTORIA

Submitted by Puerto Rico's EHDI Team

During this funding period, the Puerto Rico Newborn Hearing Screening Program started the family support group “*Grupo de Apoyo Victoria*” in 2013. “*Grupo Apoyo*” is Spanish for “support group” and Victoria is the poster girl for our group. Victoria was born in 2011 and didn’t pass her newborn hearing screening at birth. Our service coordinator contacted her mother and by her third month of age, she was diagnosed with bilateral hearing loss. Our team worked hard and fast with Victoria’s mother, and by her 5th month of age, she was already using hearing aids. With Victoria we showed that our 1-3-6 goal really can be met! Victoria’s mother has been an active family leader ever since.

The *Grupo de Apoyo Victoria*’s goal is to unite families who have children that are D/HH in an informal manner to talk and exchange information about their experiences, worries and needs. For each meeting, our team includes one professional resource such as: an audiologist, speech therapist, psychologist, occupational therapist, teachers from school for the deaf and more recently, an audiologist who is also a specialist in rehabilitation. These professionals present valuable information and answer questions that the parents might have in the various fields of expertise. Before the COVID –19 pandemic, these meetings were held quarterly, by region, in person and during working hours, making it difficult for some parent to attend. But COVID-19 most definitely changed everyone’s life. Given the inability to meet in person, we started exploring virtual options to continue with the family support group. After carefully assessing the availability and options for the parents, a recurrent virtual meeting was established for 7 pm on Fridays. This has become one of our biggest accomplishments since the attendance has more than tripled since these virtual meetings started. Without the hassle of taking time off work and by overcoming other barriers that limited the parents to attend the meetings, we have had the chance to reach out to more families and their response has been great! This has been a great example of how a challenge became a hidden opportunity.

In addition to the virtual meetings, we continue to have our Family Based Organization working hard on all sorts of other tasks for family support. For us, *Grupo Apoyo Victoria* has been a great accomplishment and has allowed us to incorporate new technologies that have facilitated and expanded our reach. Getting a chance to be helpful in a more accessible setting has been the best that COVID-19 has brought to PR EHDI.