

CHARGE On



In 2013 I was at a point in my life in which I felt I was stable enough to offer help to others in need and I was eager to find volunteer opportunities. My primary desire to help was based on a personal promise I made after the loss of my two children. The promise was that I would do anything in my power to help parents and their special needs children know there is someone that can understand what they are going through. As a Neonatal Intensive Unit (NICU) mom, I knew firsthand that feeling of uncertainty, of living life on a day-to-day basis and, at times, losing hope. Ensuring other Moms know they are not alone is an ongoing life goal. One parent, one child and one act of kindness at a time. With this in mind, I enlisted in a journey of a lifetime.

My search for volunteering opportunities in the community lead me to The CHARGE Syndrome Foundation. CHARGE is caused by mutations in the CHD7 gene on chromosome 8. "CHARGE" refers to a specific set of birth defects, medical problems, and developmental issues. The most distinctive birth defects are coloboma, choanal atresia and characteristic ears (external ears and small/absent semicircular canals). There is no relationship to sex, race, nationality, religion, socio-economic status, or prenatal exposure. My opportunity with the CHARGE Syndrome Foundation would come in the form of helping with their children's camp.

The Foundation, including its biennial conference, is an indispensable resource for many of its members. It is a place to look for information, support, research and access to other parents and professionals. This allows parents the opportunity to gain a better understanding of their child's diagnosis, managing their condition and coping with the diagnosis.

Fast forward six years and three conferences later I am the official CHARGE camp nurse. During each conference, while parents attend the different breakout sessions the kids attend camp. Going to camp may be fun and seem uncomplicated, however, when you add ventilators, tracheostomies, feeding tubes, hearing aids, cochlear implants, behavioral and developmental issues, camp can be nerve

wracking and unsettling to any parent. As a camp nurse it is my role to not only keep children safe but to reassure parents of the same. Beyond ensuring the children are safe, having the opportunity to interact with kids with CHARGE is one of the most rewarding things one can do. Despite all of their medical challenges, these kids just want to be kids. Children with CHARGE syndrome often far surpass the medical, physical, educational, and social expectations placed on them. It is inspiring to hear the parents of children with CHARGE talk about the indomitable spirit, the humor and the compassion of their children. Parents are eager to be in a place where they are not judged or criticized for providing necessary care for their children. During this year's 14th International Conference, a mother summed it up perfectly. "Emotional as I leave the island. An island where hearing aids, glasses, canes, wheelchairs, walkers, traches, feeding tubes, tics, tantrums are looked at with a kind smile and word of encouragement rather than clearing the room." Each conference offers families the opportunity to bond and come closer. They all experience and share similar emotions and challenges. Individuals with CHARGE are family! Watching every parent or family care for each other as if they were their own, without judgment and with compassion is beautiful.

No matter your title, role, socio-economic status or talent, I encourage you dig deep and consider looking for volunteer opportunities in your community. Not only will it be rewarding for you, but you can make an unimaginable impact on someone else's life as well.

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Diana Lenís



