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## El Oído Una publicación gratuita de Partners for A Greater Voice

#### Edición VI- 2015

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Partners for a Greater Voice fue establecida como una corporación sin fines de lucro. Proporciona ayuda y apoyo a los países en vías de desarrollo que eligen enseñar a niños sordos o con pérdida auditiva a cómo hablar. "Partners for a Greater Voice" colabora con los padres, instituciones y organizaciones que abogan por el conocimiento de la salud de la audición, experiencias de integración y educación auditivo verbal y oral.

*Expandiendo el mundo de un niño sordo o con problemas de audición* ©

## Thank you... Joanne Travers, MIM

I am pleased to offer our last issue of El Oido that focuses on the parent and includes results from our parent education survey we conducted in 2014. Working in the Dominican Republic has been more than rewarding in over twelve years of service, and I appreciate everyone who has participated in our training and education initiatives.

Partners for A Greater Voice (PGV) and 65 volunteer partners completed 28 missions in support of teachers, practitioners and parents of children who are deaf and hard of hearing in San Pedros de Macoris, La Romana, Boca Chica, Santo Domingo, Moca, and Santiago. Our missions involved over 1000 Dominicans and several missions included United States based learning experiences. The scope of our education in hearing health and habilitation included early intervention, auditory verbal therapy and emerging literacy workshops as well as missions to start a school, build therapy rooms, test the hearing of children, and donate hundreds of hearing aids. I am fascinated with the impact on children, teachers, parents, audiologists and technicians we worked with.

I am grateful for the support of professionals at Instituto de Ayuda al Sordo Santa Rosa, in particular Onelia Aybar and Casilda Jimenez - two of the most gracious and supportive educators of the deaf who remain committed to fostering the full potential of children with hearing loss. Teachers Yadixa Messina Alvarez, Sonia Matos and Maria also participated and went above and beyond, benevolently sharing what they learned with many others, including parents. I am also grateful for the families of Boca Chica, and in particular Estebania Concepcion who dedicated seven years of service. She established Centro Asistencia para Sordo San Andres (CASSA) and worked with Diorka Nolasco who directed the school with vigor and drive. PGV will forever embrace the hearts of teachers



that we trained at CASSA: Mercedes Yohannis Zapata, Estella Rivera, and Tomasa Rodriguez. We coached and trained Jacqueline Batiste and Nancy de la Cruz as Parent Consultants who compassionately engage families in San Andres. Estella Maria Rivera is now an aural habilitation specialist working at Hospital Elias Santana where PGV constructed and equipped an auditory verbal therapy room. We appreciate the collaboration at Hospital Elias Santana and thank Nicole Hunter and all staff members who convey the importance of parent participation and habilitation, including audiology technicians Manuel Evangeliste, Genesis Troncoso and Misael Restituyo. Our hearts extend lovingly to the teachers of Santa Rosa, Moca, Centro Asistencia Experimental Sordos (CAES) and to the 500 plus parents who traveled far for at least one of our parent workshops and meetings.

Parents drive my determination and passion to coach and educate others. Knowing parents have each other instills hope and a belief that anything is possible for children with any degree of hearing loss. I hope that everyone who came in contact with PGV and our 65 volunteer partners learned as much from us as we learned from you.

Peace and Kindness, Joanne N. Travers, MIM, CiPP;

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#### **Power to the Parent!**

David Luterman, Educator of the Deaf and Parent Counselor, advocated for parents of children with hearing loss regardless of chosen communication methodology. In the mid 1960s David started a Family Center at Emerson College in Boston, Massachusetts (USA) specifically to support parents. He knew back then that parents were not coming to grips with their child's hearing loss and that they did not have a safe place to share in their grief. Professionals knew then that parent participation was essential for improving outcomes of children learning language, and David knew a focus on treating the parent was needed.

Before founding Partners for A Greater Voice, I started Parent Connection in Massachusetts in 1996 (currently a Chapter of the Alexander Graham Bell Association for Deaf and Hard of Hearing) soon after learning of my child's hearing loss. I am of the next generation of David Lutermans and for ten years I spearheaded parent and family events, workshops and conversations with parents. I listened to their stories, their worry, and grief. Educating

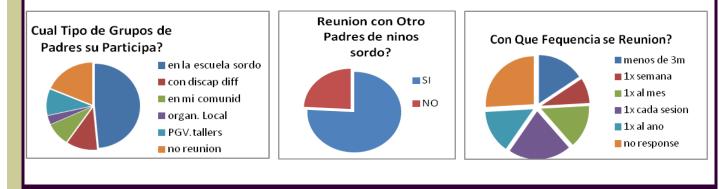
and supporting other parents would become my life's purpose. I held the power to transform the life of my own children, as well as the lives of a hundred other parents raising children with hearing loss.

I carried the Parent Connection experience with me on every mission in the Dominican Republic. Meeting with and listening to over 500 parents became a priority. Like David Luterman, I believe treating the parent is most important. Parents innately know their children and dream their children will thrive: get an education, have friends, find work and eventually start a family. With deafness, their dreams are often shattered. Inside the swollen hearts of many parents, their emotions swirl about. I see parents all over the world lost in grief. Many have limited or no place to go to for support and accurate information.

Getting parents and caregivers together ignites something special. They reveal their apprehension, their grief, their worry, and vulnerability. Meeting together provides a sense of belonging and is safe for sharing stories. Parents are a wealth of information, and parent gatherings are educational, broadening and affirming.

Parent groups are not new, but they can be hard to organize and sustain. In the United States our PGV survey revealed that over 90% of parents feel that getting in touch with other parents is valuable. In the Dominican Republic, over 80% of Dominican parents we surveyed said they have participated in parent meetings.

After fifty years of parent group support. David Luterman believes a transfer of power to the parent is necessary. To transfer that power to the parent, everyone working in the field of hearing health and habitation must work together, teaching and learning from parents. Coach parents to be leaders of their child's development. Embrace and foster a parent's strengths. Treat parents like partners, and encourage parent to parent conversations. Every parent has the power to help their child reach his/her full potential.◊



#### Edición VI- 2015

#### Parent Empowerment

Learning about hearing loss and raising a child with hearing loss is not linear; the process is multi dimensional. Becoming educated about hearing technology, education options, parenting a child and navigating disability rights is a journey. Parents need to be vigilant in the acquisition of knowledge, but be patient that understanding and knowledge evolves over time.

A conceptual framework for parent-to-parent support was recently published by Shiela Moodie and Henderson in the American Journal of Audiology (2015). It identifies the Learning Parent (parents who learn from other parents) and the Supporting Parent (parents who support other parents). In group settings, there are always parents we learn from and always those who teach. Parents often play both roles! A Supporting Parent is capable of educating other parents. Being empowered means a certain degree of knowledge has been acquired and a feeling of competence and confidence instilled. As a Learning Parent, feeling empowered means that one can adapt,

engage, make decisions and find solutions that are best for parent, child and family.

Clinicians, teachers, and physicians help to foster empowerment by accurately informing parents. Decisions on deaf education, hearing access, and disability rights must involve parents (as well as deaf and hard of hearing persons) and conversations must reflect a parents beliefs and values. Listening to parents is critical, regardless of income or level of education. As clinicians, teachers, and physicians inform parents, they also need to embrace a parents well-being.

Treating parents first is critical, and it extends beyond a parent's grief. Holding parents accountable and expecting them to be leaders of their child's development requires walking alongside them, coaching them on things they are capable of doing, and feeding them as much information as they are ready to hear and absorb.

The power is in the hearts of parents where passion can surface with strength, resilience, confidence, and leadership.  $\diamond$ 

## Parents! Take charge!

#### Break Stigma

It is often society's view of the disability that prevents children from reaching their potential, where beliefs and attitudes are ingrained on the streets and doorsteps of neighbors. In the Dominican Republic, I first heard that deaf children were Deafmute, 'sordomudo" stupid, unworthy. It was these labels of the Deaf that everyone referred to. I saw this as an opportunity to change attitudes and beliefs, and I corrected people by replying, "Anything is possible for a Deaf child. They are not stupid or mute."

I met grieving parents in their homes. Some of them sheltered their children from public ridicule and physical abuse. Some parents abashedly hand their children over to orphanages or Deaf schools just to be freed from the burden and grief.

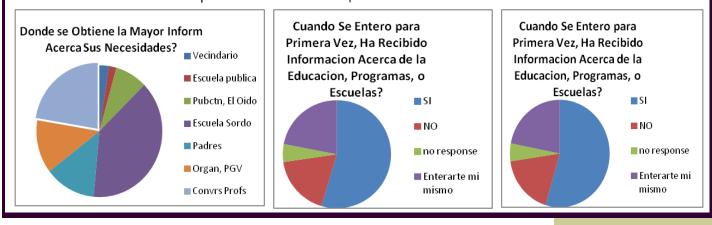
All children need a parent's



attention and love. Children with hearing disability need greater consideration, encouragement, socialization, language, and affection from the parent. A child's social, emotional and cognitive development is dependent on the caregiver. Children need to feel valued, just as parents need to feel valued.

Listen up Parents! Become courageous and determined to seek help, focus on learning as much as you can about hearing loss, be supportive of your child's emotional and social needs. Continue to learn, open your heart, and be strong with your beliefs.

For social change to occur, parents who raise their children to their fullest potential can foster self advocacy skills, and as children grow older they become part of a social movement to break stigma. ◊



#### El Oído

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## **RESULTS OF PGV SURVEY**

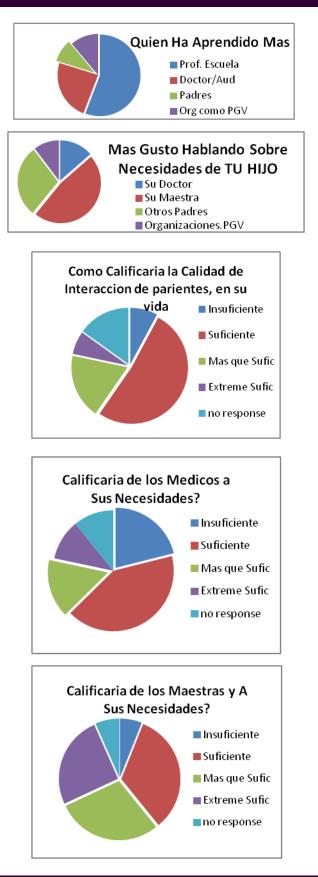
In 2014, Partners for A Greater Voice surveyed parents and conducted Positive Psychology workshops in Boca Chica, San Andres, San Pedro de Macoris, Santo Domingo, and Los Alcarrissoz. More than 120 parents participated, and a total of 166 surveys were compiled. It is important to note that parents of all levels of social economic status participated. The survey supported twelve years of qualitative data and facilitated the creation of *Essential Programs to Coach and Empower Parents*. Of 166 written responses to 38 questions, 70% were mothers, 17% were fathers, and others were grandparents, aunts and siblings. Approximately 40% had public university or advanced degrees. Parents reported a majority of children have bilateral hearing loss in the severe to profound range, and have no suspicion of another disability. ◊

Parents rely on mostly doctors and teachers for information about hearing loss and how to care for their child. The majority are most comfortable speaking with teachers (55%) and doctors (27%); however many were sufficiently comfortable talking with either. Dominican parents have a harder time coordinating regularly scheduled parent meetings due to transportation and/or family and work obligations, which is why learning from other parents is not high on the list (only 13%) and why talking with doctors and teachers is more prevalent.

PGV has learned that most low income parents have limited access to hearing health services and parent support. These parents (and their children) often feel isolated. The majority ask for parent training and workshops (81%). The majority (78%) said the quality of interaction with parents was either sufficient, more than sufficient, or extremely sufficient.

It may be surprising to find that only 5% of parents feel high or extremely high degrees of stress when caring for their child with deafness, given the fact that there is less disability services, limited education, and higher levels of discrimination. Culturally, families learn to cope with adversity and hide their burden. Resilience is high. PGV has witnessed that low income families are often burdened with basic needs. Caregivers do not focus on the disability so much as other needs within the family. In many instances, a child's disability is ignored or needs are 'put off'. Social, emotional and language development is compromised as a result. PGV predicts that a level of stress will increase as parents become more involved in the child's education, advocacy initiatives, and social change. In the United States, for example, where disability laws and spe-

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#### El Oído

### Learning to Listen? Is It For Your Child?

In 2012 I learned that the Ministry's Department of Deaf Education mandated bi-lingual education across the country, in all schools. Spanish and sign language had to be taught, no deviation. I am saddened by the fact that parents in the Dominican Republic still have limited options in education for the Deaf. During a parent meeting in 2012 PGV embraced the reality of what was going on in schools at the time. One mother expressed, "My older daughter comes home and says, 'Mama, I don't want to use my hands. I want to use my voice!"". How can this be? I think. Is authority taking away a child's communication interest? At another meeting, parents succumb to whatever is available. "We are grateful to have a school nearby to send our children and that they are learning."

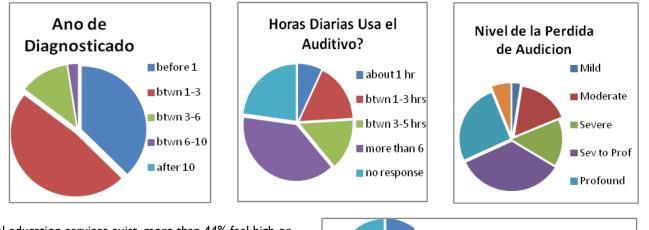
I know, in twelve years of conversations with over 500 Dominican parents, most of them want to their children to talk. Ninety-five percent of parents with children born deaf are hearing and over 90% of these parents chose listening and spoken language (LSL), according to a US study release years ago. For LSL to happen, parents must put the hearing aid or cochlear implant on the ears of their children during all waking hours. Many profoundly deaf children often do not benefit from a hearing aid and need a cochlear implant to hear speech sounds and conversational language. If cochlear implants are not

financially feasible, then parents have options: lean to lip read, learn sign language, or advocate for hearing health benefits from the government.

If listening and spoken language is the goal, then learning to listen is the first step. Listening with hearing technology takes practice, and speaking occurs when the child is immersed in aural language. Parents must find time to talk with their children. Early identification and language immersion are essential! The younger a child with hearing loss is identified and treated (hearing technology, aural habilitation, learning to listen), then the greater their potential in spoken language. Newborn hearing screening programs are ideal.

Listening and spoken language is a choice, just as bilingual and sign language are chooses. Results of the PGV survey revealed that 25% of parents did not know their options. It is important to immerse a child in fluent, rich language, either listening or sign. I believe schools should be set up to accommodate different communication interests, and schools should be equipped to support different learning needs of children. Not all deaf children are alike and regardless of the degree of hearing loss, parents and their children have rights. Transferring the power to the parent is the right concept, but it will take time for Dominican parents to come together, to act on their power and demand communication and education options be made available to their children.  $\diamond$ 





cial education services exist, more than 44% feel high or extremely high levels of stress. Even still, children in the United States are finishing high school, attending colleges, and are employed more than ever before. As adults, they advocate for access and education services to support them.  $\Diamond$ 



btwn 3-5 yr
no response

∎btwn 1-3 yrs ∎more than 6 yrs Agradecemos profundamente a nuestros patrocinadores. Para participar en el patrocino de esta boletín favor de contactar Joanne Travers:

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#### ESTE BOLETÍN DE NOTICIAS ESTA PUBLICADO POR PARTNERS FOR A GREATER VOICE

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## Coaching and Empowering Caregivers of Deaf and Hard of Hearing Children, *a Partners for A Greater Voice Program*

Healthy, happy, and well adjusted parents mean healthier, happier, well adjusted children.

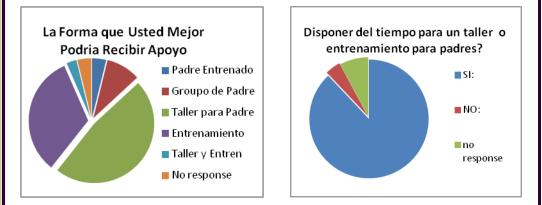
Partners for A Greater Voice (PGV) offers a unique, interactive program designed to educate caregivers. This program is based on eighteen years of qualitative experience and results compiled from parent surveys. Joanne Travers, founder and director, leads this innovative program with six essential education modules to:

address hearing health & habilitation target specific parental needs for emotional health prepare parents for their journey to raise their children

PGV's program successfully coaches and empowers caregivers based on their capacity and resources, with the additional goal of promoting sustainable outcomes for aural deaf and hard of hearing children. Six modules focus on specific education in hearing health and aural habilitation. Activities and exercises are woven throughout the program to coach parents on how to become leaders of their child's development while fostering physical health and emotional well being.

Caregivers are most influential in a child's social, emotional, and cognitive development. Good outcomes in language and social skills necessitates caregivers have good self perception, better psychological health, and high family function. These constructs are incorporated into *Essential Programs for Coaching and Empowering Caregivers*. The program provides learning experiences needed to effectively parent and care for a child's hearing loss, and foster education, language, social skills and emotional intelligence.

Email or call Partners for A Greater Voice to schedule your seminar. PGV offers a day-long seminar for professionals and six, five hour seminars for parents.



## **Convention for Rights of Persons with Disabilities (CRPD)**

CRPD was adopted in 2006 at the United Nations Headquarters in New York, and is the first comprehensive human rights treaty of the 21st century. There are currently 159 countries who have signed the treaty including the Dominican Republic. The Convention follows decades of work by the United Nations to change attitudes and approaches to persons with disabilities. It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. With more than one billion persons affected with disability worldwide, strong disability groups emerge to not only protect the rights of persons with disability, but to uphold social, emotional and intellectual potential.