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FAMILIA CHARGE- LESSONS LEARNED ON SUPPORTING SPANISH-SPEAKING FAMILIES

OBJECTIVES

- Understanding of how culture impacts engagement
- Share our strategies, successes, and successes in progress.
- Share lessons learned
- Potentially replicate some of these strategies in your area.





A LITTLE BIT ABOUT ME

WHAT IS CHARGE SYNDROME?

CHARGE SYNDROME IS A RECOGNIZABLE GENETIC SYNDROME WITH KNOWN PATTERN OF FEATURES. IT IS AN EXTREMELY COMPLEX SYNDROME, INVOLVING EXTENSIVE MEDICAL AND PHYSICAL DIFFICULTIES THAT DIFFER FROM CHILD TO CHILD. CHARGE SYNDROME IS CORRELATED WITH GENETIC MUTATION TO CHD7 AND THE PREVALENCE OF CHARGE SYNDROME IS 1:10,000-1:15,000 LIVE BIRTHS.

LEARN MORE AT CHARGESYNDROME.ORG



C COLOBOMA OF THE EYE(S)
H HEART DEFECTS
A CHOANAL ATRESIA
R RESTRICTION OF GROWTH
AND DEVELOPMENT
G GENITAL ABNORMALITIES
E EAR ABNORMALITIES/
DEAFNESS

Gideon Bloodgood, age 12



CHARGE SYNDROME

- Rare Genetic Syndrome- 1 in 10,000 births worldwide
- Clinical Diagnosis
- Medically Complex
- Wide range of severity
- Deafblindness and its impact on education
- Families live in constant stress, specially during the first 5 years of life.



CHARGE SYNDROME FOUNDATION

- National Organization with a Global reach
- Website- information hub for families and professionals- www.chargesyndrome.org
- Facebook Group with over 9,000 participants
- Virtual support groups, parent leaders, assistance programs, research and more!

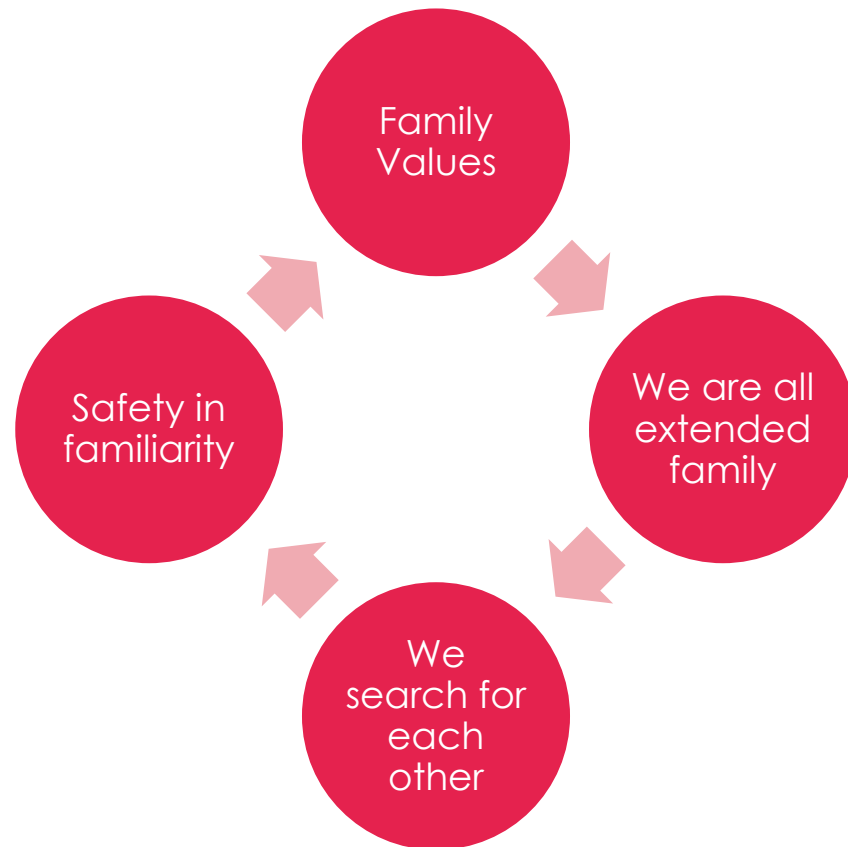


LATIN AMERICANS LIVING IN THE US

- Language barrier
- Cultural differences
- Isolation
- Lack of knowledge about disability
- Challenges navigating the system
- Search for hope
- Living in fear



OUR CULTURE



- Language and cultural barriers impact everything in our lives
- Adding a rare diagnosis can be overwhelming
- "It is rare to find a family like mine"
- Difficulty navigating the system.
- Sometimes we feel invisible.
- But when we find our community, we thrive!

LESSONS LEARNED

- What does not work?
 - Brochures, paperwork
 - Information dumping
 - Structured interviews
 - Scheduling the same length of time as you would for an English-speaking family.
 - Literal translations of documents from English to Spanish
- What works?
 - Having someone to talk to, in your language
 - Support systems (churches, schools, other local groups)
 - Ask- what do you need?
 - TIME
 - Ask for confirmation- that they understand the information you are sharing
 - Certain Social Media apps like WhatsApp, Facebook groups

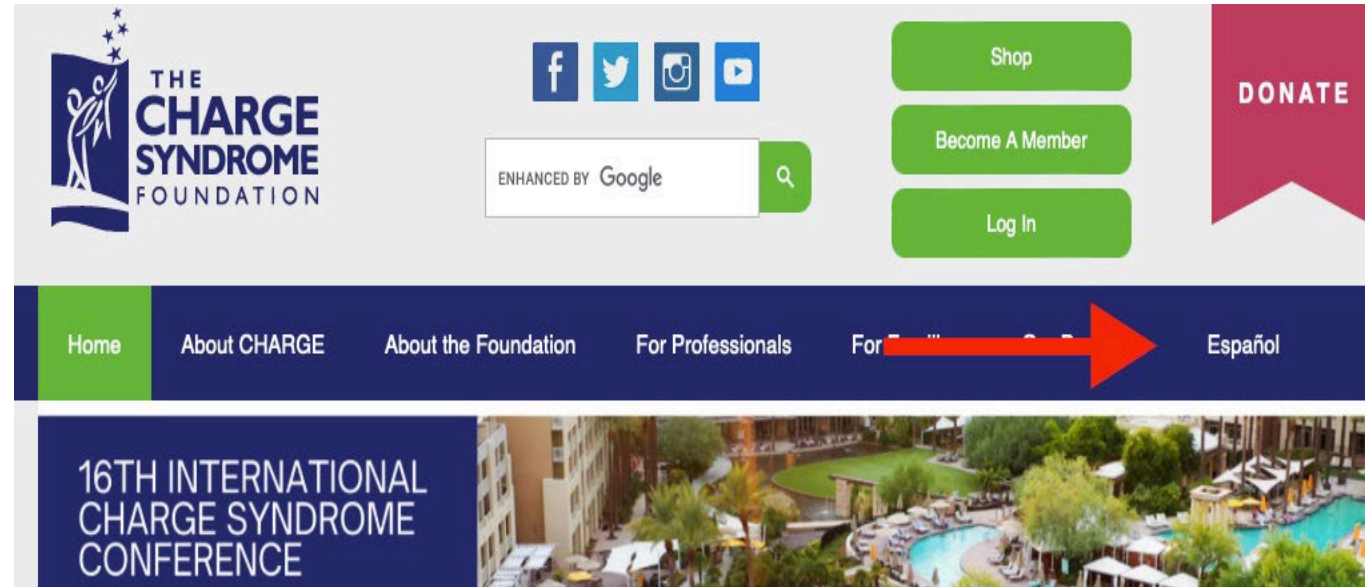
FAMILA CHARGE

- Monthly Virtual Support Group
 - "Drop-in" system
 - Same day, same time, every month
 - 2 hrs +!
 - Open to ALL families (siblings, adults with CHARGE, parents, grandparents)
 - Open to International Families
 - Mostly open-ended meetings- the group decides the topic and discussion
 - Guest speakers when necessary
 - Facebook group and WhatsApp companions



OTHER APPROACHES- OUR WEBSITE

- Dedicated section in Spanish.
- ALL webinars will be recorded and interpreted in Spanish.
- Also provide dedicated webinars in Spanish
- Links to other partners and resources.
- Newsletter in Spanish
- Program Applications in Spanish



SOCIAL MEDIA



- WhatsApp- the most effective and popular
- Facebook Groups
- Instagram
- TikTok

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PARTNERING



- Hands and Voices
- Deafblind International
- Deafblind Projects
- Parent Centers
- Local Groups
- Joined webinars
- We can do more when we help each other!



IN CLOSING...

- Successful outreach to Spanish-speaking families involves time, resources, and a system-wide change.
- It does not have to happen overnight
- Staffing that reflects your population pays off!
- Sometimes, you must put your agenda aside and just listen.
- Small adjustments can make a significant impact
- Be inclusive!
- Think outside the box
- Understand the social context
- It is now harder than ever, but it is worth the wait!

GRACIAS!

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THE
CHARGE
SYNDROME
FOUNDATION