

Bridging Cultures, Building Trust: Success Stories on Supporting Spanish-Speaking Families in the CHARGE Community

Lourdes Quintana, CHARGE Syndrome Foundation



About me



What is CHARGE Syndrome?

- Rare genetic syndrome
- Clinical Diagnosis
- Medically Complex
- Wide range of severity
- Deafblindness and its impact on education
- Families live in constant stress, especially during the first 5 years of life.

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

F EAR ABNORMALITIES/



EARLY BLOODGOOD

CHARGE Syndrome Foundation

- National Organization with a Global reach
- Website- information hub for families and professionals- www.chargesyndrome.org
- Facebook Group with over 10,000 participants
- Virtual support groups, parent leaders, assistance programs, research and more!





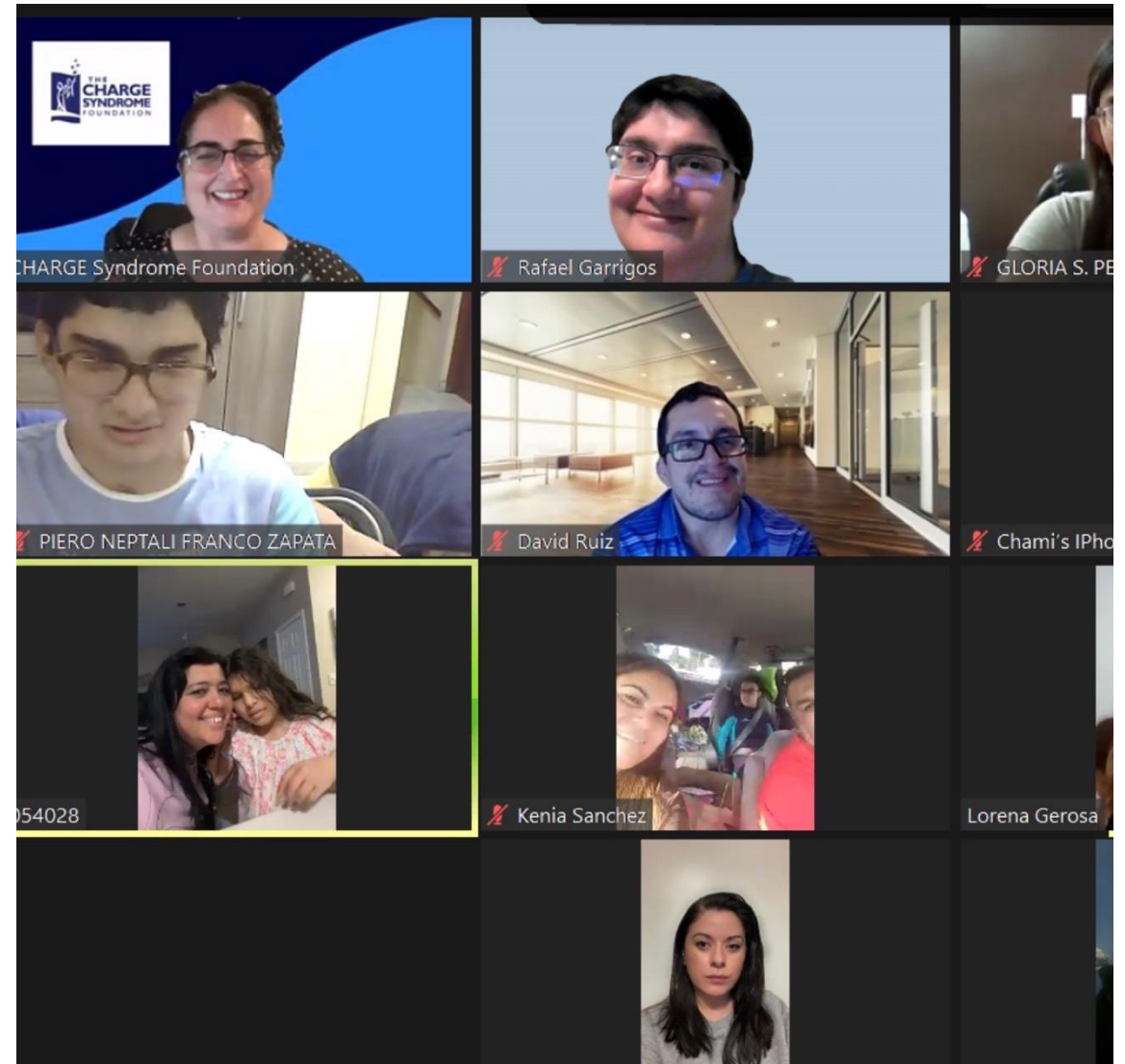
Familia CHARGE- How we started!

- 2023 Conference in Orlando
- Just a few families happy to be able to be together and to have so much in common!
- Shared our contacts and started a WhatsApp Group
- How do we keep this going?



Familia CHARGE

- Monthly virtual meetings
 - Open to all family members and individuals with CHARGE
 - Open topic sharing session
 - Same time, same day every month
 - Average length of each meeting- 2.5 hours
 - Average number of participants 25
 - Helped us build that sense of community and belonging



Building the bridge

- What worked?
 - Flexibility
 - Communication through WhatsApp
 - Open to anyone, any location
 - Partnering with other Spanish speaking professionals
 - Build relationships between meetings
 - Relationships build trust
 - Real talk about how our system works
- What did not work?
 - Structured meetings
 - Communication exclusive through email
 - Limiting it to families in the US
 - Don't spam! Limit the contact and make it meaningful

Familia CHARGE- expanding our reach

- Webinars in Spanish.
- Newsletter in Spanish.
- Opened our Facebook Group page.
- Collaborations with Latinoamerican Professionals.
- Our WhatsApp continues to grow.



Helping grow their confidence

- Allowed some parents and adults with CHARGE to lead parts of our meeting
- Had some family members present during our meeting
- Highlighting their accomplishments as a group
- Recognize that their lived experiences makes them an expert!
- There is enough room for everyone!



Experience in Conference

- First Spanish spoken presentation during our Conference-
 - Transformando Vidas: De nuestra experiencia con CHARGE a una Red de Inclusion en America Latina-
 - “Transforming Lives: From Our Experience with CHARGE to a Network of Inclusion in Latin America”





From Sidelines to Center Stage

- Representation in our sibling panel
- Representation in our adults with CHARGE panel
- Even our professionals were able to shine!

Celebrating our Culture

- Give opportunities and let the families dictate how they want to be included
- Allow families to interact in their own language
- Having a shared purpose to help each other
- It is ok to be seen!



Looking ahead

- More representation at our next Conference
- Start an Adults with CHARGE support group in Spanish
- Parent led support groups
- Professional networking
- More reach!

Conference



Save the date to join us at the Hilton Anatole in Dallas, TX for the largest worldwide gathering of individuals with CHARGE, their families, professionals and experts at the 17th International CHARGE Syndrome Conference, July 22-25, 2027!

499

22

44

23

Days

Hours

Minutes

Seconds



Thank you!

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