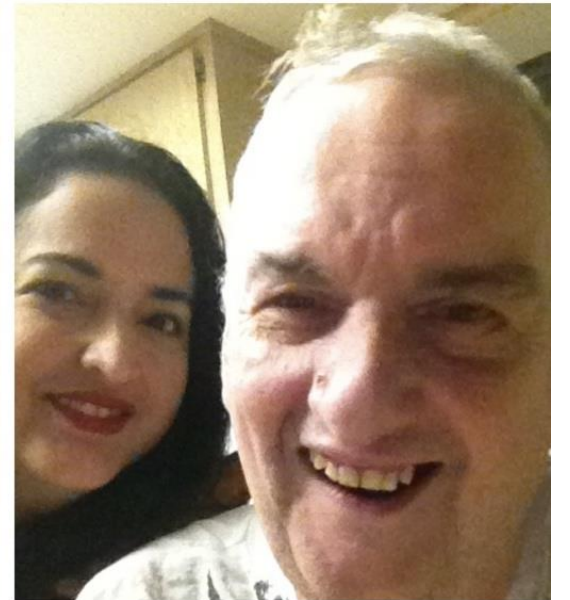
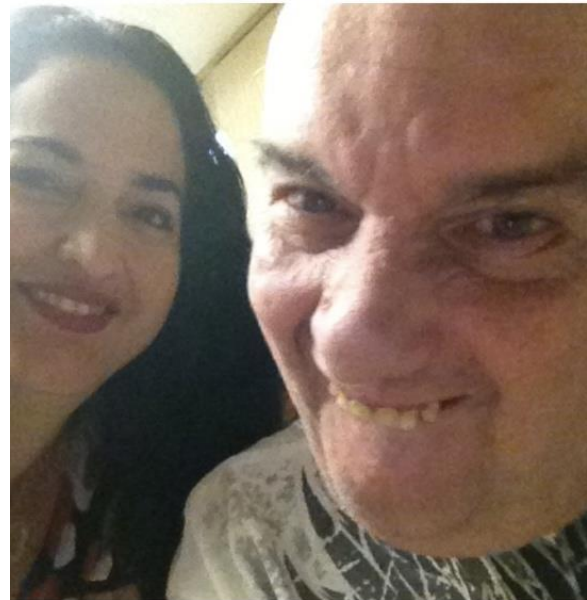
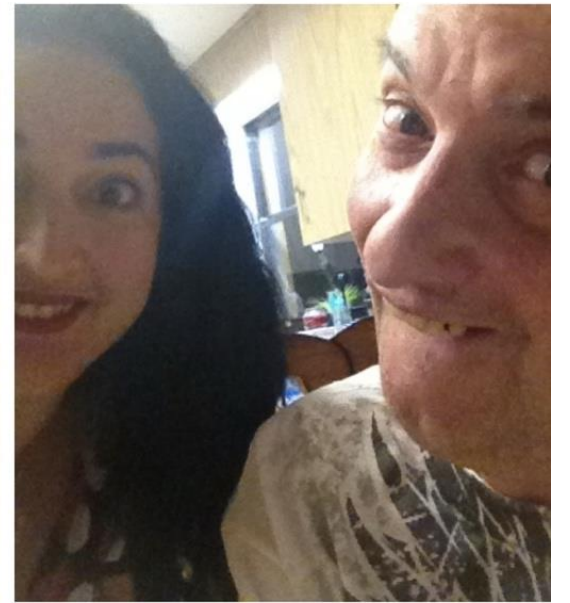


Lourdes Baez Quintana, MS  
Outreach and Engagment Manager  
CHARGE Syndrome Foundation

## Family Liaisons: Lessons on Family Leadership and Empowerment





# 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](http://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/



Gideon Bloodgood, age 12

EARLY BLOODGOOD

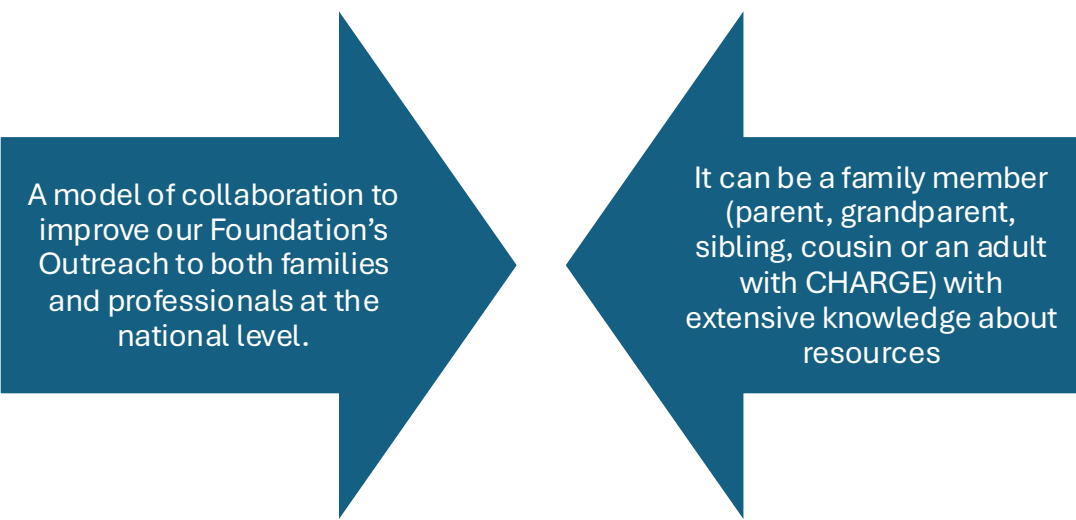
# CHARGE Syndrome Foundation

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



# Who are the Family Liaisons?



A model of collaboration to improve our Foundation's Outreach to both families and professionals at the national level.

It can be a family member (parent, grandparent, sibling, cousin or an adult with CHARGE) with extensive knowledge about resources

- The primary function of the Family Liaison is to:
  - Share the latest resources with our families
  - Assist our Foundation and partners in identifying families
  - Update our Foundation on available resources
  - Promote connections among families in their state.



# Family Liaisons

- Requirements:
  - Member of our Foundation
  - Reside in the state that they represent or be part of a special population
  - Extensive knowledge of local resources
  - Connection with local partners
  - Basic computer skills, email and access to social media
  - Attend our quarterly meetings
  - Develop action plan for activities in their state
  - Commit to serve for a period of 2 years

# Parent Leaders



We look to have a diverse representation of parents with children at different stages

Able to meet our families where they are

Willingness to connect and to shared lived experiences

# Extended family

- Siblings
- Grandparents
- Foster parents
- Cousins
  - Their level of involvement in the care for the person with CHARGE is important
  - Representation of caregiving at different
- Or Special Populations:
  - Military families
  - Spanish speaking families
  - Grieving families
  - Adopted families
  - Households with more than one person with CHARGE

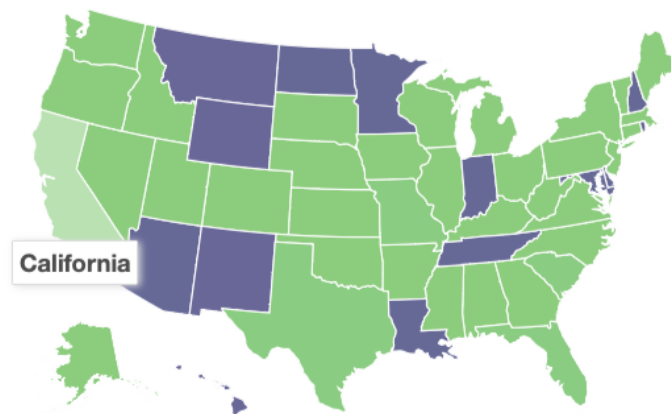
# Adults with CHARGE

- Bring a unique and important perspective
- Inspiration for new parents
- Reality check for parents
- Nothing about me without me
- Example/mentoring for older children



# Family Liaisons by State

## Family Liaisons by State/Territory



See what our Family Liaisons are up to in our [Family Liaison's Spotlights](#).

To contact your state's Family Liaison, or if you are interested in becoming a Family Liaison, please email [info@chargesyndrome.org](mailto:info@chargesyndrome.org)

*Get to Know Your State Liaison. Click on the name below.*



# Recruitment

- Recommended by community partners
- Reach out to our Foundation
- Recruited by another member of our community
- Interview
- Training that includes
  - Role and expectations
  - Navigating the Deafblind support and service system
  - Understanding our programs
  - Connecting with our key partners
  - Building your State Resource List
  - Build your outreach plan



# What do they do?

- Parent Support Groups
  - Face to face and virtual meet ups
  - Awareness Activities
  - Webinars
  - Support new parents
  - Promote family connection
  - Facilitate social media groups
- Examples of our virtual support groups:
    - Birth to Five Parent Group
    - Parent ReCHARGE Hour (2x per month)
    - Adults with CHARGE Socials
    - Familia CHARGE- support group for Spanish speakers

# Example- Birth to Five Virtual Support Group

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- The first five years in the life of a child with CHARGE can be critical
- Parents are thrown into medical parenting overnight
- Adjusting your expectations for developmental stages
- They are finding their voices and learning how to advocate for their child
- Often times new families find our website when searching for information on CHARGE

CHARGE SYNDROME FOUNDATION

## **Birth to Age 5 Parent-to-Parent Support Group**

**December 13, 2025**

5:00 PM PT, 6:00 MT, 7:00 CT, 8:00 ET



Dec 2025 Birth to 5 1.png



# Birth to Five Parent Support Group

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- Hosted by parents of a young child- recent experience
- Once a month meetings, on a set time
- Topic driven discussions
- Guest speakers
- Flexibility is key
- Open door



# Birth to Five Parents Growing Together

- Our parents are:
  - Relieved to find a group that understands their struggles
  - Learning together
  - Building bonds and friendships
  - Transition from new parent to parent leader
  - Parents of older children begin to support new parents



# Unleashing Family Leaders

- Turning lived experiences into opportunities for growth
- Build confidence
- Learn about their service delivery system while helping other families
- Integration to our community of support



# Lessons Learned

- In order to be successful, you must:
  - Be flexible
  - Constant communication
  - Communicate in different ways- email, text, social media
  - Treat it as a mentorship
  - Facilitate connections
  - Know their strengths and passions
  - Respect

- Appreciation
- Recognition
- Inclusion



Thank you!

Lourdes Quintana

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