You are not alone!

Supporting families with CHARGE Syndrome

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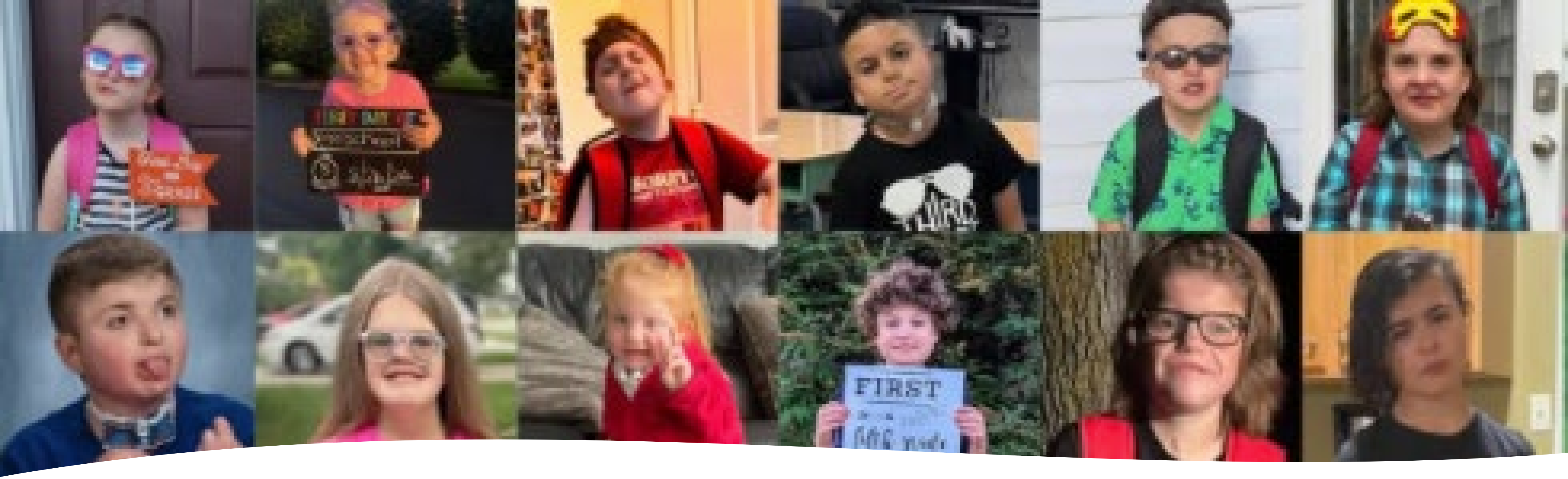
Session Objectives

- Provide a general understanding of CHARGE Syndrome
- Understand the unique situation for these families
- Share best practices to support new families
- Share strategies to better support new families
- Review strategies to outreach underserved families.

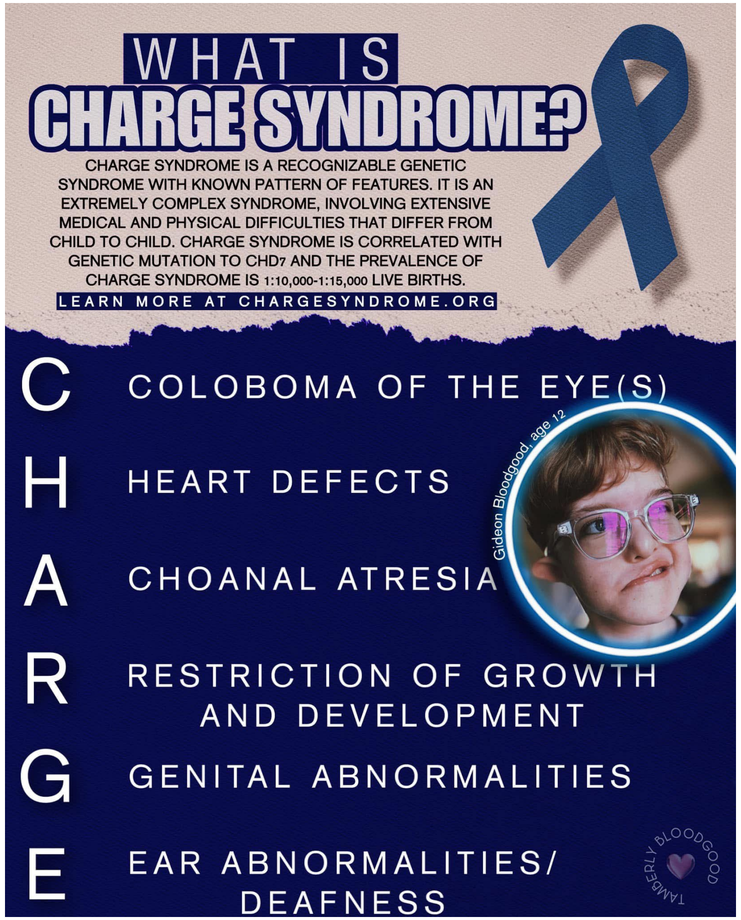
A little bit about me



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!

What is CHARGE Syndrome?



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

- 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.

Getting a CHARGE Syndrome Diagnosis

- Long NICU stay
- Multiple surgeries, ongoing battle to keep that baby alive
- Road to diagnosis can be rocky, lots of unknowns
- Medical Professionals have limited knowledge of CHARGE
- Trauma

Hearing Loss and CHARGE

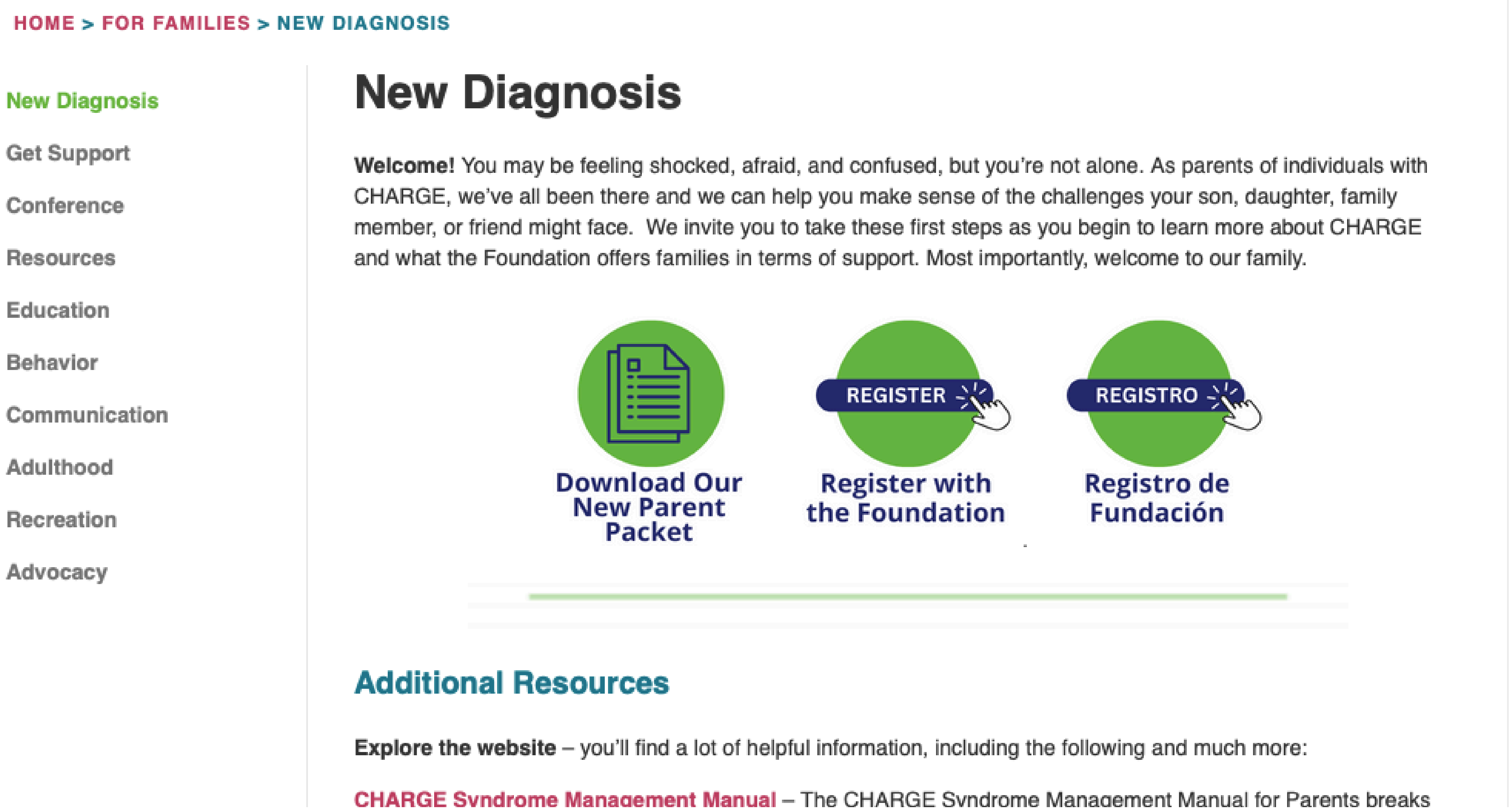
- Very from mild to severe
- Cochlear Implants
- BAHA
- Communication Options
- Deafblindness
- Competing need

Our website

- www.Chargesyndrome.org
- First experience for families
- Newly Diagnosed section with:
  - New Parent Packet
  - Registration
  - Priorities for new families video
  - Support group
  - Resources

A better world for people with CHARGE syndrome.

The CHARGE Syndrome Foundation champions the lifelong potential of people with CHARGE syndrome through outreach, education and research.



New Diagnosis

Welcome! You may be feeling shocked, afraid, and confused, but you're not alone. As parents of individuals with CHARGE, we've all been there and we can help you make sense of the challenges your son, daughter, family member, or friend might face. We invite you to take these first steps as you begin to learn more about CHARGE and what the Foundation offers families in terms of support. Most importantly, welcome to our family.

Additional Resources

Explore the website – you'll find a lot of helpful information, including the following and much more:

CHARGE Syndrome Management Manual – The CHARGE Syndrome Management Manual for Parents breaks

Welcoming new families

- First contact email
- Welcome gift
- Connect with a Family Liaison
- Connect with local resources, partners
- Connect with other families
- Keep it short and sweet!

Family Liaisons

- By State
- Parent leaders who connect with families on their state to share information, resources and support
- Volunteers
- Connected to local partners and the CHARGE Syndrome Foundation

Why peer to peer support is important?

- Share experiences
- Learn from each other
- Bonding
- Credibility
- Sense that they are not alone on their journey

Support Groups

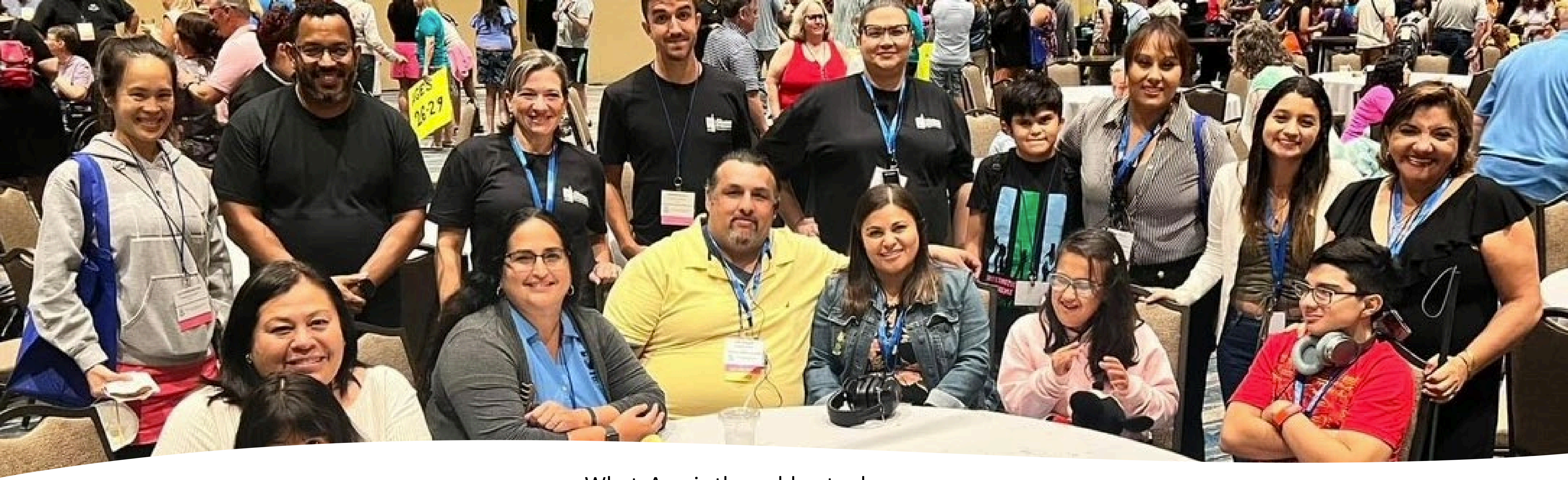
Facebook group (main)

Birth to Five Virtual Support Group

Birth to Five Facebook group

CHARGE virtual support groups

Familia CHARGE



Outreaching Spanish Speaking families

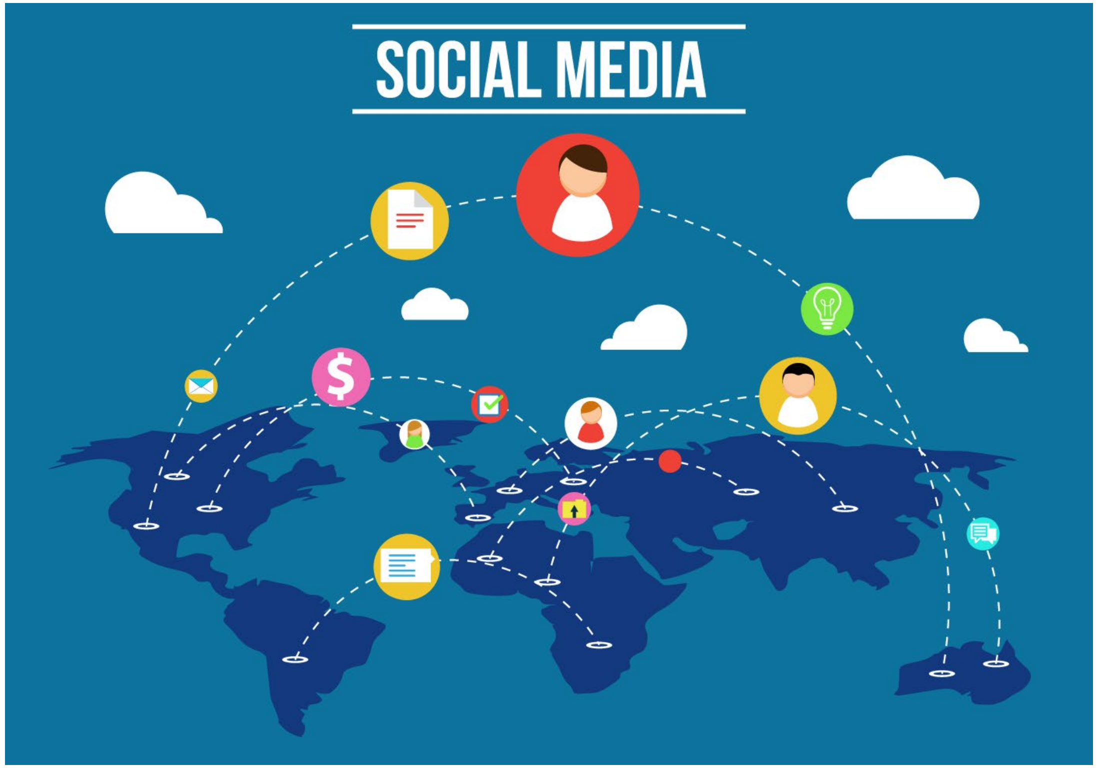
- WhatsApp is the golden tool
- TIME
- Open to international families
- Our Foundations' commitment to providing access;
  - Spanish section on website
  - Webinars
  - Newsletter
  - Staff

Lessons learned from our support groups

- Distance is not an issue
- Flexibility is key
- Consistency is key
- We do not have to have all the answers
- Stories are powerful

Social Media and CHARGE Syndrome

- Gives us access to the world
- Helps educate others on daily struggles and in the diagnosis
- Endless possibilities
- Our strategies include:
    - Main Facebook group
    - Specialized Facebook groups
    - Instagram/TikTok
    - Whatsapp



THE GRAND ADVENTURE

RISING FROM CHALLENGES TOGETHER

16th International CHARGE Syndrome Conference

Phoenix, Arizona • July 24-27, 2025

The 16th International CHARGE Syndrome Conference, "The Grand Adventure," will be held at the JW Marriott® Phoenix Desert Ridge Resort & Spa, in Phoenix, AZ , July 24-27, 2025.

International CHARGE Syndrome Conference

- July 24-27, 2025 in Phoenix, Arizona.
- Rotate locations every two years
- Our Foundation offers covers registration and child care for all individuals with CHARGE.
- Our Foundation provides scholarships for registration for family members and hotel stay.
- We also offer professional scholarships, fellowships and more!

In closing

- Families with a rare diagnosis can feel isolated.
- Not all traditional approaches will work.
- Their challenges are unique.
- Building relationships is a key component!
- The earlier, the better!
- Parent leaders can play an important role.
- Patience.
- Educate families and professionals to prioritize hearing needs
- Use all resources at hand!

Thank you!

THE CHARGE SYNDROME FOUNDATION

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