

# Thriving with CHARGE Syndrome: A Family Perspective on Supporting Medically Complex Infants

**Thriving with CHARGE Syndrome:**  
A Family Perspective on Supporting Medically Complex Infants

Tuesday, March 15, 2022  
3:50 PM - 4:15 PM  
Room 3



1

---

---

---

---

---

---

---

---

**welcome**

**Penni Echols**

Nevada Hands & Voices  
ASTra Advocate, Parent Guide  
Leadership to Leadership (L2L) Program Graduate of 2021

**CHARGE Syndrome Foundation**  
Board of Directors  
Nevada Parent Liaison

**National Family Association for the Deafblind**  
Lifetime Member  
Ambassador

**Martha's Mom**  
& her 5 beautiful sisters



Calico Basin, Nevada

2

---

---

---

---

---

---

---

---

**welcome**

**Families:**  
You are not alone and your story matters.

**Early Intervention Providers:**  
Thank-you for teaching parents that we are capable.

**State Healthcare and Education Agency Representatives:**  
Thank-you for showing us that every child can reach their full potential.

**University Faculty and Students:**  
We need you, please don't give up.

**Healthcare and Medical Providers:**  
Thank-you for facilitating miracles.

3

---

---

---

---

---

---

---

---

**desired outcomes**

**1**  
Better understand life with a deafblind and medically complex infant

**2**  
Demonstrate the importance of parental self-efficacy

**3**  
Encourage connection with family-to-family support organizations

4

---

---

---

---

---

---

---

---

**outcome 1**

**Better understand life with a deafblind and medically complex infant**

5

---

---

---

---

---

---

---

---



**NICU life**

- High drama
- Born a survivor of a high-risk pregnancy
- Known congenital heart defect
- Open-heart surgery at 7 days
- Gastronomy tube placed at 7 weeks
- 3 newborn hearing screenings with 3 different results
- Discharged at 9 weeks, plan to return at 6 months of age for more extensive heart repair.

6

---

---

---

---

---

---

---

---

# Thriving with CHARGE Syndrome: A Family Perspective on Supporting Medically Complex Infants



### home life

- New kid and new equipment in the house
- Back log of responsibilities
- Discovered many additional medical complications, multiple ER visits, cardiac catheterization, second open-heart surgery, airway repair
- Health declined until 11 months
- Breathing was still too noisy for an ABR and she was a high risk for sedation
- Worked on ASL as a family, found myself really frustrated with it

7

---

---

---

---

---

---

---

---

---

---

### follow-up care

<b>Medical Providers</b>	<b>Community Therapy</b>	<b>Early Intervention</b>
<ul style="list-style-type: none"> <li>Pediatrician</li> <li>Cardiology</li> <li>Gastroenterology</li> <li>Nutritionist</li> <li>Pulmonology</li> <li>Orthopedic Surgeon</li> <li>Genetics</li> <li>ENT</li> <li>Audiology</li> <li>Ophthalmology – Vision</li> <li>Ophthalmology – Retina</li> <li>Optometry</li> <li>ER for respiratory distress</li> </ul>	<ul style="list-style-type: none"> <li>Occupational Therapy 2x30 min/week</li> <li>Physical Therapy 2x30 min/week</li> <li>Speech Therapy 2x30 min/week</li> <li>Feeding Therapy 1x30 min/week</li> <li>Family Counseling w/Chaplin 2x45 min/month</li> <li>Ortho lab/Cranial Band 1x month</li> </ul>	<ul style="list-style-type: none"> <li>Occupational Therapy 1x45 min/month</li> <li>Physical Therapy 1x45 min/month</li> <li>Speech Therapy 1x30 min/week</li> <li>ASL family learning 2x60 min/month</li> <li>Feeding Therapy 1x 45 min/month</li> <li>Developmental Specialist 2 x 60 min/month</li> </ul>

8

---

---

---

---

---

---

---

---

---

---



### appearance

### reality

<ul style="list-style-type: none"> <li>Social supports dissolved</li> <li>New family priorities</li> <li>Extreme fatigue</li> <li>Pressure at work after time out of office</li> <li>Increased demands</li> </ul>	<ul style="list-style-type: none"> <li>Guilt</li> <li>Greif</li> <li>Shame</li> <li>Expectation to resume previous commitments and activities</li> </ul>
-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	----------------------------------------------------------------------------------------------------------------------------------------------------------

9

---

---

---

---

---

---

---

---

---

---



10

---

---

---

---

---

---

---

---



11

---

---

---

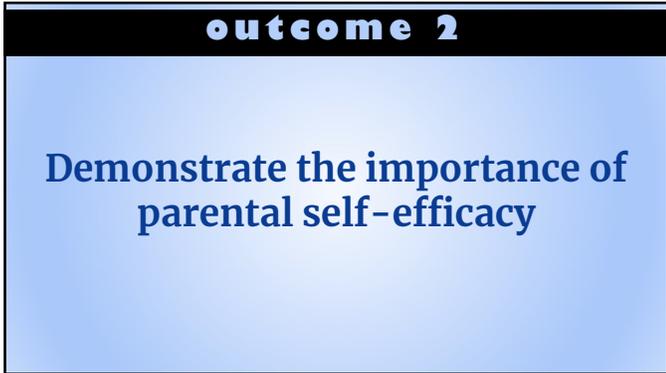
---

---

---

---

---



12

---

---

---

---

---

---

---

---

“Perceived self-efficacy is defined as people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives.

Self-efficacy beliefs determine how people feel, think, motivate themselves and behave.

Such beliefs produce these diverse effects through four major processes. They include cognitive, motivational, affective and selection processes.”

Bandura, A. (1994). Self-efficacy. In V. S. Ramachaudran (Ed.), *Encyclopedia of Human Behavior* (Vol. 4, pp. 71-81). New York: Academic Press.

**self-efficacy**

13

---

---

---

---

---

---

---

---

---

---

**mastery experiences**

“The most effective way of creating a strong sense of efficacy is through **mastery experiences**. Successes build a robust belief in one's personal efficacy.”

- Celebrate small victories
- Ignore timetables and milestones and focus on progress
- Debrief difficult situations to recognize what went right



14

---

---

---

---

---

---

---

---

---

---

**social persuasion**

- Create a safe space
- Provide a roadmap
- Be honest
- Be persistent
- Troubleshoot as needed
- Provide accountability

“In addition to **raising people's beliefs** in their capabilities, they structure situations for them in ways that bring success.”



15

---

---

---

---

---

---

---

---

---

---

**vicarious experiences**

- Cultivate diversity
- Don't be afraid of social media to make connections
- Provide mentors  
P2P support is the gold standard
- Encourage attendance at national and regional diagnosis specific conferences

“Seeing people similar to oneself succeed by sustained effort raises observers' beliefs that they too possess the capabilities to master comparable activities required to succeed.”



16

---

---

---

---

---

---

---

---

**outcome 3**

**Encourage connection with family-to-family support organizations**

17

---

---

---

---

---

---

---

---

**it seems obvious**

<p><b>early intervention providers can:</b></p> <ul style="list-style-type: none"> <li>• Team up for home visits</li> <li>• Make personal connections</li> <li>• Share success stories</li> <li>• Volunteer with family organizations</li> </ul>	<p><b>family organizations can:</b></p> <ul style="list-style-type: none"> <li>• Provide a variety of activities and information sources</li> <li>• Be accessible</li> <li>• Participate in systems level work</li> <li>• Be patient</li> </ul>
--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------



18

---

---

---

---

---

---

---

---

# Thriving with CHARGE Syndrome: A Family Perspective on Supporting Medically Complex Infants

**resources**

- Link to definition:  
<https://www.uky.edu/~eushez/Bandura/BanEncy.html>
- Bandura, A. (1994). Self-efficacy. In V. S. Ramachaudran (Ed.), Encyclopedia of human behavior (Vol. 4, pp. 71-81). New York: Academic Press.
- Bandura, Albert. *Self-Efficacy: The Experience of Control*. Worth Publishers; 1<sup>st</sup> edition.
- [www.chargesyndrome.org](http://www.chargesyndrome.org)
- [www.nvhandsandvoices.org](http://www.nvhandsandvoices.org)
- [www.handsandvoices.org/resources/dhh-plus](http://www.handsandvoices.org/resources/dhh-plus)
- [www.chargesyndrome.org](http://www.chargesyndrome.org)
- [penni@chargesyndrome.org](mailto:penni@chargesyndrome.org)



---

---

---

---

---

---

---

---

19