

# ADDITIONAL SUPPORTS

for families with a child who is deaf  
or hard of hearing and additional  
medical or developmental needs





# welcome

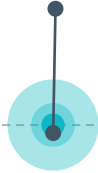
## Penni Echols

- ▶ Martha's Mom (and her sisters too)
- ▶ ASTra Advocate & Parent Guide, 2021 L2L Graduate, *Nevada Hands & Voices*
- ▶ Nevada Liaison & Member on Board of Directors, *Charge Syndrome Foundation*
- ▶ Ambassador, *National Family Association for Deaf-blind*
- ▶ Parent Representative, *NDE Special Education Advisory Committee*



# LEARNING OBJECTIVES

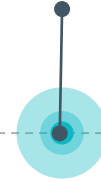
**Describe 2 unique needs of families with infants who have medical needs**



Identify 3 sources of support for families of infants who are Deaf Plus



Locate 2 state/local providers of diagnosis specific support for families



## MARTHA'S ORIGIN STORY: Tiny Superhero

- ▶ High risk pregnancy
- ▶ Threatened miscarriage at 14w
- ▶ Growth deficiency at 16W
- ▶ Heart condition recognized at 24W
- ▶ Genetics seemed fine from amnio
- ▶ Heart condition would require open heart surgery at 7 days

**Maternal Stress HIGH**



## MARTHA'S ORIGIN STORY: Tiny Superhero

- ▶ 6 days old before being held
- ▶ 7 days old open heart surgery
- ▶ 4 weeks old failure to thrive
- ▶ 5 weeks old congestive heart failure
- ▶ 7 weeks old gastrostomy tube placement
- ▶ 9 weeks old referred hearing screening
- ▶ 9 weeks old discharged from hospital

**Infant Stress HIGH**



## MARTHA'S ORIGIN STORY: Diagnosis was a long road

- ▶ Newborn screening 3 times
- ▶ 3 failed outpatient ABR attempts
- ▶ No audiologist at preferred hospital
- ▶ T-tubes, T&A removal at 10 months
- ▶ Imaging: absent semicircular canals, bilateral mondini and deformities of the ossicles at 11 months
- ▶ Sleep deprived ABR at 13 months
- ▶ Aided at 14 months
- ▶ Official CHARGE syndrome diagnosis at 15 months

### **DELAYED diagnosis**



## New reality: CHAOS

- ▶ Left hospital EVERY DAY at 2:30 so I could pick up my other kids and feed them dinner
- ▶ Repeated episodes of respiratory distress and trips to the ER
- ▶ New kid and new equipment - everywhere
- ▶ Unsure of prognosis
- ▶ Increased demands on parents and siblings
- ▶ Schedule and activities did not return to normal



## New reality: We could not keep up

- ▶ Social supports dissolved
- ▶ New family priorities
- ▶ Extreme fatigue
- ▶ Pressure at work after time out of office
- ▶ Workplace culture not amenable to FMLA
- ▶ Understanding of co-workers and partners wore thin after 6 months
- ▶ I was asking him to be a decision partner, but I didn't give him information
- ▶ Financial concerns related to medical bills

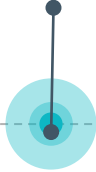
**Paternal stress HIGH**



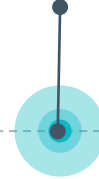


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## A FEW OF MY FAVORITE THINGS

- ▶ NOT exhaustive
- ▶ Intended to get you thinking



## GOVERNMENT AND WELFARE AGENCIES

- ▶ **State Medicaid**
- ▶ **Katie Beckett Waivers**
- ▶ **Social Security Office**
- ▶ **Regional Center**
- ▶ **Governor's Disability Council**
- ▶ **State Commission for the Deaf**



## MEDICAL RESOURCES

- ▶ **Regional Genetics Networks**  
<https://nccrcg.org/>
- ▶ **Shriners Children's**  
<https://www.shrinerschildrens.org/en>
- ▶ **Family Navigation Network**
- ▶ **Office of Minority Health and Equity**



## EDUCATIONAL SUPPORT

- ▶ **Early Intervention Intake**
- ▶ **Child Find Intake**
- ▶ **Early Childhood Technical Assistance**
- ▶ **Parent Training and Information Center**
- ▶ **Local library - special needs library services**



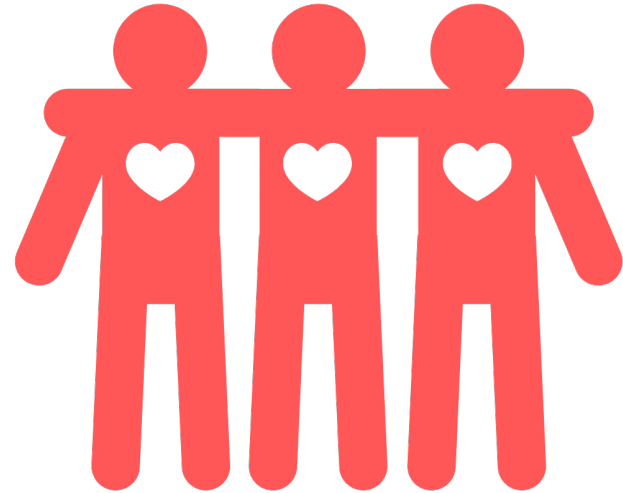
## DEAFBLIND NETWORK

- ▶ **State Deafblind Project**
- ▶ **National Center on Deaf-Blindness**
- ▶ **National Family Association for Deaf-Blind**
- ▶ **Helen Keller National Center**



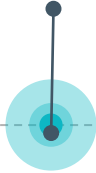
## SOCIAL AND RECREATIONAL SUPPORT

- ▶ **Caregiver Action Network**  
[caregiveraction.org/about](https://caregiveraction.org/about)
- ▶ **Lighthouse Guild**  
[lighthouseguild.org/support-services](https://lighthouseguild.org/support-services)
- ▶ **National Organization for Rare Disease**  
[rarediseases.org/living-with-a-rare-disease/](https://rarediseases.org/living-with-a-rare-disease/)
- ▶ **Hands & Voices DHH Plus Parent Facebook Group**  
[facebook.com/groups/deafhardofhearingplus](https://facebook.com/groups/deafhardofhearingplus)
- ▶ **Local Facebook Groups**



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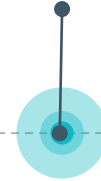
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# DIFFICULT PROMISE TO KEEP

- ▶ Hope to inspire you to make connections
- ▶ This is the purpose of the CHARGE Syndrome Foundation's Liaison Program

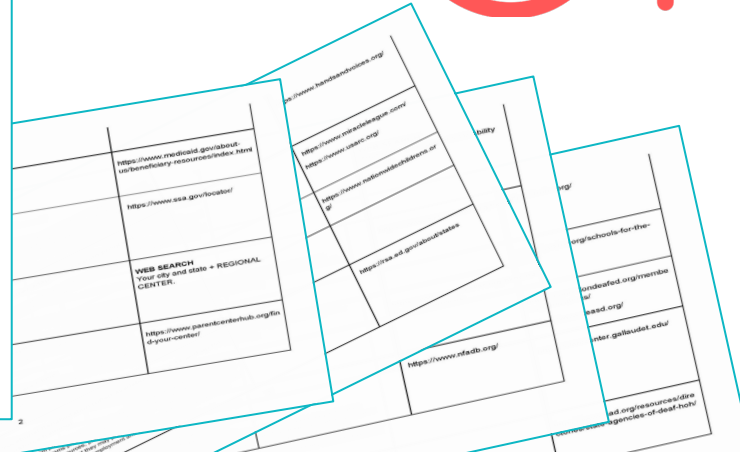



  
 Date Updated: <</2022>>

<<ENTER YOUR STATE>> State Resource List  
 <<ENTER YOUR NAME>>, Family Liaison <<ENTER EMAIL>>, <<ENTER PHONE#>>

Resource Name & Description	Contact Name & Title	Website & Phone number
<b>State Deafblind Project</b> State deaf-blind projects provide a range of services to improve results for children with deaf-blindness and their families.		<a href="https://www.nationaldb.org/state-deaf-blind-projects/">https://www.nationaldb.org/state-deaf-blind-projects/</a>
<b>Early Intervention Intake</b> The intake/screening step in the early intervention process is often the first face-to-face contact with the family. The intake/screening involves an interview with the parents to understand what concerns, if any, the family has.		<a href="https://www.parentcenterhub.org/oi-overview/">https://www.parentcenterhub.org/oi-overview/</a>
<b>Child Find Intake</b>		<a href="https://agesandstages.com/about-asq/who-uses-asq/child-find/">https://agesandstages.com/about-asq/who-uses-asq/child-find/</a>

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## DIAGNOSIS SPECIFIC RESOURCES

- ▶ **Autism speaks**
- ▶ **National CMV**
- ▶ **Everylife Foundation for Rare Disease**
- ▶ **GFPD**
- ▶ **Down Syndrome Society**
- ▶ **NORD**
- ▶ **Usher Syndrome Coalition**
- ▶ **CHARGE Syndrome Foundation**
- ▶ **Connect families when you can in a meaningful way**  
**“Could you share ONE thing that helped you the most in the first 6 months?”**



## BUILD YOUR OWN NETWORK

- ▶ **Invite organizations to provide training**
- ▶ **Host joint family events**
- ▶ **Ask families what they need**
- ▶ **Support community events**
- ▶ **Like/Share/Follow on social media**
- ▶ **Create relationships not spreadsheets**

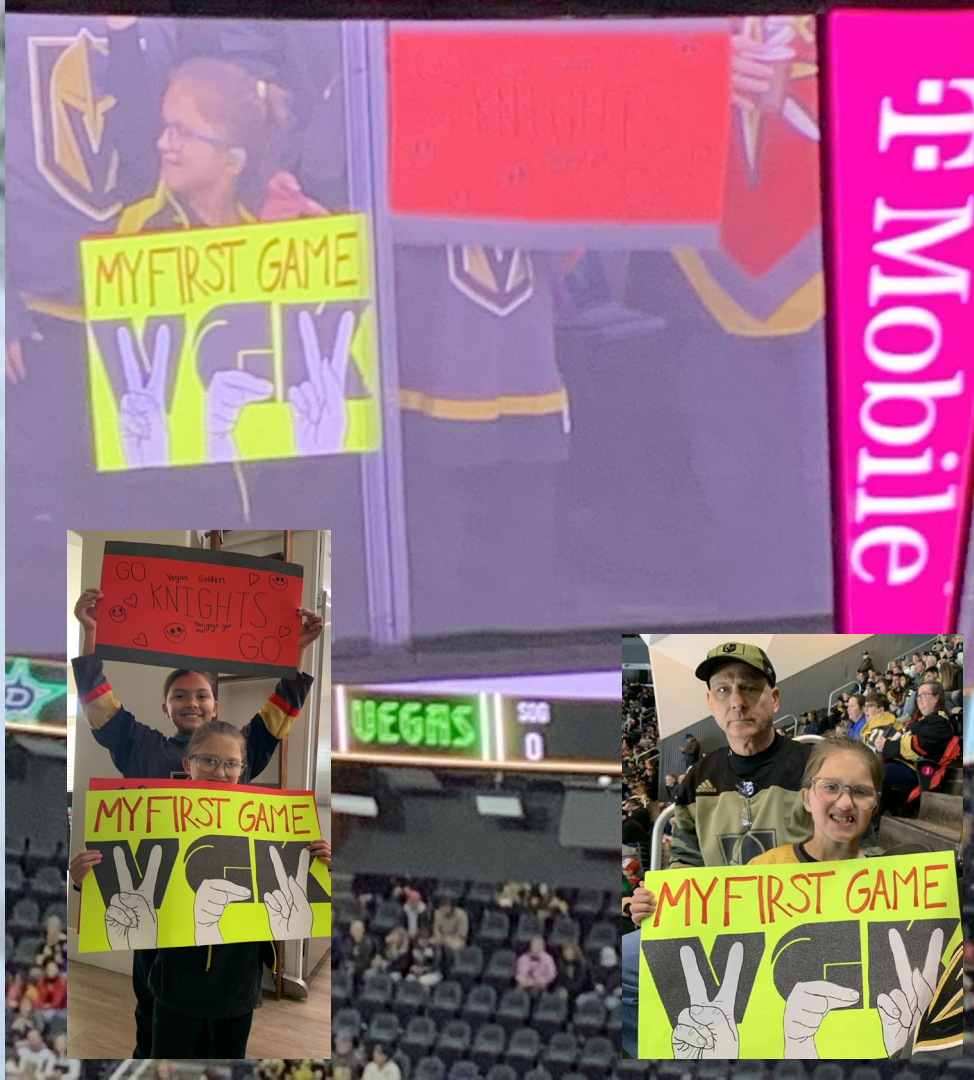


***The best and most beautiful things in the world cannot be seen or even touched. They must be felt with the heart.***

*Helen Keller*

*June 8, 1891; Letter to the Reverend Phillip Brooks*





# YOU ARE NOT ALONE

Reach out if you need a reminder!

Penni Echols

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