



Getting Real: Parents Sharing their Journey through Early Elementary School

Wednesday, April 14, 2021

Parent Presenters:
Penni Echols, Nevada
Michelle Milder, Georgia

Overview of Our Time Together

- Welcome
 - Add to the chat box the state you are from & one burning question you have
- Penni and Michelle will share their family journeys
- Conversation/Open Discussion

Meet Penni and her family...

Echols Family

Established 2000

Outnumbered in 2006

Out-handed in 2008

“Embracing the Weird” since 2014





How it Started

- HighER risk pregnancy
- Threatened miscarriage at 14w
- Growth deficiency at 16W
- Heart condition FINALLY recognized at 24W
- Fetal monitoring alone made me too busy to handle life with 5 kids
- Genetics seemed fine from amnio
- Severity of heart condition had us worried. Planned for open heart surgery at 7 days



Daily Life - survival

- 9 weeks in NICU/PICU
- Left hospital EVERY DAY at 2:30 so I could pick up my other kids and feed them dinner
- Grandmas dropped everything to help out
- Church family fed us 4 times a week for 4 months
- Discharged at 9 weeks old, with g-tube and plans for second open heart surgery at 6 months old

Falling Apart



- NOTHING went as planned
- Constant respiratory distress and trips to the ER
- Feed intolerant
- Making discoveries about hearing, vision, craniofacial abnormalities and GI tract
- Waitlist for Medicaid Waiver
- Unsure of diagnosis
- Unsure of prognosis

TRAUMA Tidal Wave

- Providers have a very hard time understanding the tidal wave of responsibility that falls on the family of a complex child.
- We do not have a sufficient vocabulary to express how we are feeling.
- We cannot articulate what we need.
- Sometimes - magic happens and we can find a way to make things work.



Lifeline #1: Nurses who teach

(when PARENTS are ready to learn)



Let me

show you how to use firm pressure to **calm** her and **help her relax.**

During night shift,
I'll have an RT **help move her**
safely to you while her linens are changed.



Lifeline #2: Church Family



“In tough times families will either pull together to get over the mountain or they will fall apart. Your family can do this and we will help!”

~Bishop Bud Stoddard

Lifeline #3: Palliative Care

“Martha does not belong only to you! She is a sister, a granddaughter, a neighbor, a niece, a patient, and a cherished friend. Stop hogging her!”

~Chaplin Scott Oakley,
ProCare Hospice

“I cannot wait to
discharge this girl!”

~Ciearra Beals Mendoza,
Hospice Nurse





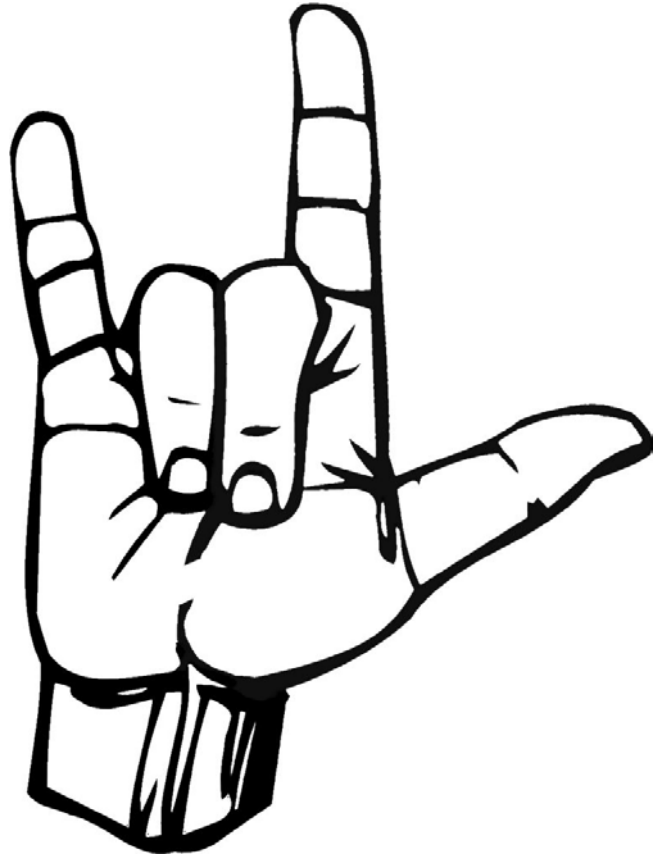
Lifeline #4: Sibling Involvement

-you've got to train your replacement-

- Need to BOND with each other
- There is something EVERY sibling can do
- Use questions to gauge readiness
- Soothes anxiety to help
- They teach, advocate, and support
- EMPOWER them with real explanations
- PRAISE them for their strength



Lifeline #5: Parent to Parent Support Networks



**One routine at a time.
One handful of signs at a time.
All the hugs you can give.**
*~Summer Wright, Guide by Your Side
(Nevada Hands & Voices)*

How it's going



YOU ARE NOT ALONE



chargesyndrome.org

Penni Echols
Nevada Parent Liaison
702.232.5379 call/text
nevada.charge.syndrome@gmail.com



Penni Troth Echols

Wife, mom to 6 beautiful daughters,
CHARGE Syndrome Foundation Nevada
Liaison.

6monkeymama 9+



162
Posts

270
Followers

Penni Troth Echols

Life is a beautiful mess. 6 daughters, you
#chargesyndrome. ASTra Advocate with
@nevadahandsandvoices.
Fitness giggles @t.h.e.sweatsisters.

. . . . reach out if you need a reminder

Meet Michelle and her family...

Stella was born in 2014 and has grown into an amazing 6 year old!

She is my one and only, but loves and adores her Grandma and Aunt Sarah!



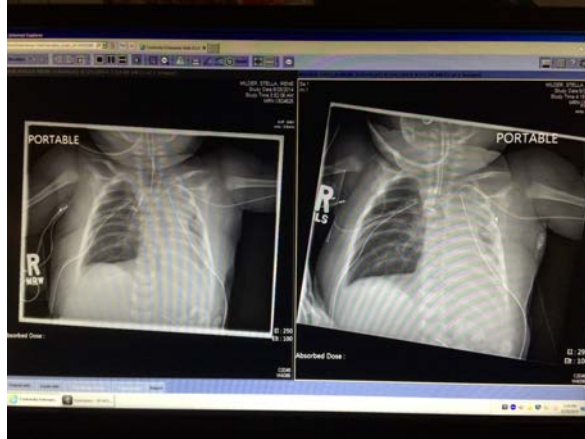
The start of our journey:

I was induced at 38 weeks. I knew about Stella's Esophageal Atresia before she was born, but did not get her CHARGE Syndrome diagnosis until 1 month old. The transport team was waiting to take her to the Children's Hospital before they even took me into the OR.



115 Days in the NICU:

Our NICU stay was filled with ups and downs. Stella's surgeon came in the day after we got her vision diagnoses and expressed how we were feeling rather poignantly..."You just keep getting struck by lightning".



Appreciate the good days:

We had so many 'curve balls' as Stella's medical team liked to say. So I was always sure to celebrate the little things. And I took pictures of everything. I took a picture every single day of her stay, with the exception of two days, September 17th and 18th.



Tip #1 - For Parents

Ask Questions!! Ask all the questions. All the time. If you don't understand the answer, ask again. If the doctor or specialist won't or can't explain it in a way you understand, ask for someone else!



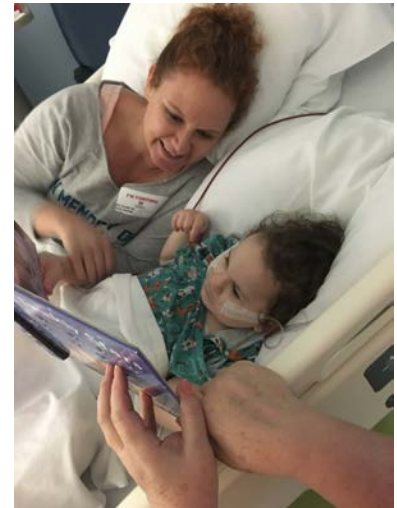
The ups and downs kept coming...

Once Stella was discharged I did all I could do to deal with the stress...I 'managed' Stella. I set up calendars, made a binder, put tabs all over it. Made lists. Set appointments. Stella has had 48 surgeries and procedures in her short 6 years. Most of which, did not go as planned.



These warriors endure things we could not even imagine...

And Stella usually does it with a good attitude and a smile on her face. And if she's upset, it can usually be fixed with a good song or some 'squishies'. She never ceases to amaze me.



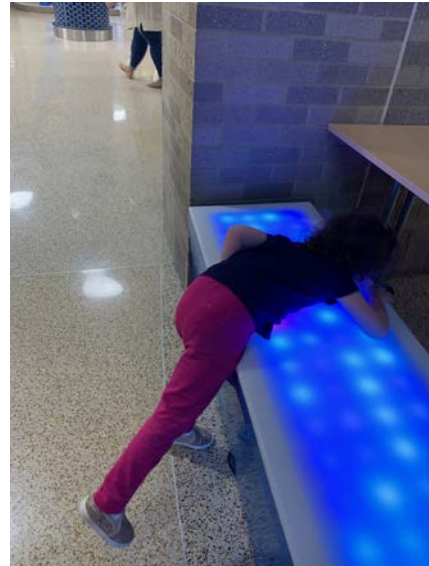
Tip #2 For Parents

Throughout all of the hospital stays and visits, my goal was to always try and keep the hospital a 'fun' experience. I knew we would be spending a lot of time there, and my goal as Stella's mother is to try and minimize the trauma involved with each visit. Stella gets excited to go to the hospital...she gets excited for v-ravel



The hospital and doctors can be fun!

When we would have an appointment at the hospital, I would always plan in extra time (if possible) to have lunch, get ice cream, play in the 'Zone' or even just look at the fish tank.



Tip #3 - For Parents and Providers

Set up a team you are comfortable with. A team who asks questions. When they ask questions about your child and their complexities it conveys an interest in understanding that child and a stronger desire to see the child grow and progress. Don't discount a parent's knowledge...Likewise, don't discount a therapist's knowledge.



Tip #4 - Celebrate all the things!

I always keep in the back of mind, how much harder Stella has to work to do things we all take for granted. How much harder it is for her to write, walk, talk, understand what people are saying, read a book! Because of this, I make it a point to celebrate every little inch-stone!



Tip #5 - Work as a team!

When working with teachers and therapists in the school setting, we often set ourselves up for battle before it even begins... because we hear how it typically goes. There always seems to be a fight for services. A fight for what is in the best interest of the child. A fight to follow a wonderfully written IEP. Listen to the input, think on it, evaluate it...then respond. Remember...and remind them...we are all on the same team!



Tip #6 - Don't be afraid to take them anywhere and **EVERYWHERE** *possible!

I take Stella everywhere I can safely do so! She wanted to see the stars but couldn't see them in the night sky, so off to the planetarium we went. She wanted to go on the 'underground' (aka the subway) so I planned a special trip downtown one afternoon. Teach them in any way they can access it!





Tip #7 - Find your go-to friends!

Seek out and cherish those friendships that are rooted in understanding and support! Find that core group who understands your life, your traumas (we all have them!) and loves and accepts you and your beautiful child, as you are!



Destined to be best buddies!



Tip #8 - Embrace the new!

The CHARGE family that I was welcomed into, with open arms, providing endless understanding, support and advice, was by far the biggest blessing!



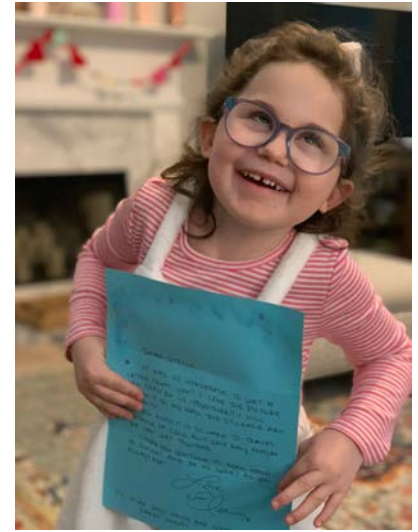
Tip #9 - Seek out the experts!

Not just your local doctors, but explore the resources that the CHARGE Syndrome Foundation, and the CHARGE Community at large has to offer. This goes for parents and providers. Their combined wealth of knowledge and experience is invaluable.

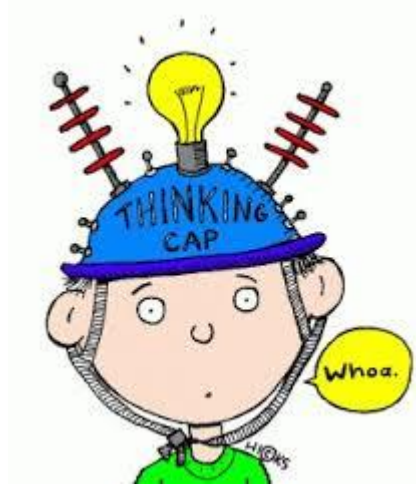


Tip #10: These kids can soar!

Don't ever put limits on what someone says your child will achieve!



Conversation/Open Discussion



Important Links

[CHARGE Syndrome Foundation Website](#)

[CHARGE State Family Liaison](#)

[Walk and Roll](#) (May 15, 2021)

[The Show Must CHARGE ONline](#) (July 16-18, 2021)

[EWRAP](#) (rolling applications)

[Family Assistance Program](#) (rolling applications)

[CHARGE it for CHARGE](#)

Thanks for joining us!