



# BEST NEWS

Blind Early Services TN - Newsletter for Caregivers and Providers



## THE LIFE AND LEGACY OF A DISABILITY RIGHTS PIONEER

*"Disability only becomes a tragedy when society fails to provide the things we need to lead our lives — job opportunities or barrier-free buildings, for example. It is not a tragedy to me that I'm living in a wheelchair." -Judy Heumann*

Judith "Judy" Heumann, widely known as "the mother of the disability rights movement" passed away at the age of 75 on March 4th, 2023 leaving behind a legacy that continues to advance the inclusion of those with disabilities both in the U.S. and around the world. After contracting polio as a child, Judy began using a wheelchair for mobility. Denied the right to attend school because her wheelchair was considered a "fire hazard" and later in life, denied a teaching license based on a failed medical exam, Judy took a stand and became a lifelong advocate and leader for the rights and independence of those living with disabilities. Judy sued the Board of Education over her denied teaching license and went on to become the first wheelchair user to become a teacher in the state of New York. Judy was instrumental in helping to develop and pass landmark legislation such as Section 504 of the Rehabilitation Act and the Individuals with Disabilities Education Act (IDEA). To learn more about Judy's impact on disability rights look for:

**MARK YOUR CALENDAR!**

MARCH 28  
7:00PM CT  
NFB TN  
PARENT DIVISION MEETING

APRIL 1  
10:00AM CT  
JACKSON, TN  
EASTER "EGG-SPLOSION" HUNT

APRIL 5  
6:30PM-7:30PM CT  
PARENT CONNECT  
VIRTUAL SUPPORT GROUP MONTHLY MEETING

APRIL 13  
12:00PM CT  
ASK THE TVI:  
EARLY INTERVENTION SERVICES

- *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist*
- *Rolling Warrior* (a young adult version of Judy's memoir)
- *Crip Camp: A Disability Revolution* (an Oscar-nominated 2020 documentary featuring Judy)
- *Lives Worth Living* (a documentary about the history of the disability rights movement)
- Judy's TED talk from 2016, "Our Fight for Disability Rights - and Why We're Not Done Yet"
- Judy's podcast, *The Heumann Perspective*
- Apple TV's forthcoming biopic based on Judy's life and memoir

### BEST Family Feature

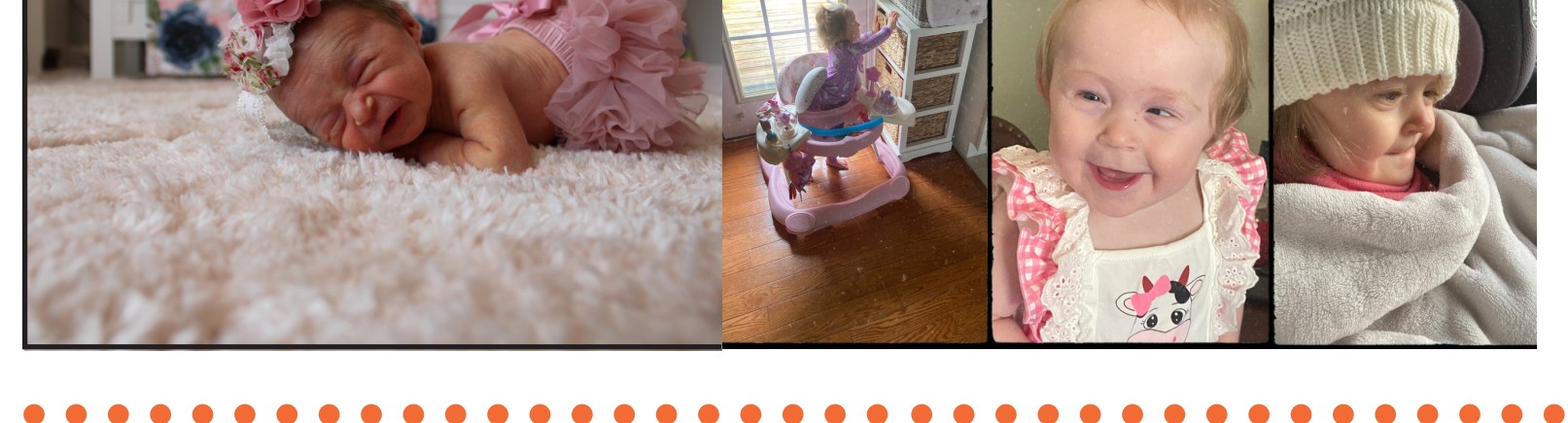
by Jennifer McMahan

Lillian Ruth was born weighing 5lbs 12oz at 37 weeks due to me having pre-eclampsia. She was a healthy little baby other than having hypothermia and hypoglycemia. After a couple days in the NICU, we got to bring our little baby home. 24 hours later, we were back in the hospital because her bilirubin levels were high and she needed to be under the bili light.

The first 6 weeks we were just enjoying the life of a newborn and then our world turned upside down. Lillian started having seizures. She was immediately treated with seizure medication and within 24 hours, seizures were gone. Fast forward to 2 months later, she started having seizure-like episodes that I had not seen before. They would come in clusters of about 50 every time she would wake up or if she was falling asleep. Her arms would sling out, her head would drop, and she would cry. We rushed her to the hospital and she was diagnosed with infantile spasms. It took a few weeks to get them under control with medication.

At about 5 months of age, I felt like Lillian wasn't looking at things or people like a baby her age should. We took her to an ophthalmologist and she was diagnosed with cortical visual impairment which is very common with babies that have suffered infantile spasms. My husband and I had never heard of this and were at loss on what to do. We were afraid our little girl would never see.

We live in the eastern part of Tennessee and couldn't find anyone that could help Lillian because of her age. We were told by our intervention services about the BEST program. I immediately emailed Alison and within 24 hours she replied back. Lillian was 11 months old at the time and wasn't looking at us or playing with her toys. After speaking and meeting with the BEST team, I started to realize that there is hope and my baby can improve! We have been doing weekly virtual session with our TVI, LeeAnn, and she has been amazing. She has provided us with so much information, materials, tips, and ideas to help Lillian. Each week, Lillian does something new. She is now 20 months old and is looking at us, playing with her iPad, playing with her toys (usually throwing them), and overall has improved significantly. She would not be where she is today visually without the help of LeeAnn and the BEST program.



### Jackson, TN Hosting Easter Egg Hunt for People Who Are Blind or Visually Impaired

This Saturday, April 1st, from 10am - 4pm at the Jackson Baseball Stadium, the Jackson Police Department in partnership with the City of Jackson, the STAR Center and Rockabillies Baseball will be hosting their first annual Easter "EggSplosion" Hunt. The Easter egg hunt will be a FREE, fun event for people who are blind or visually impaired and their families. Beeping eggs built by the Police Department's bomb unit will give individuals an opportunity to listen and hunt for candy-filled eggs. Games, activities and concessions will also be available. Register at the link below.

The Jackson Police Department  
in partnership with the City of Jackson, the STAR Center, and Rockabillies Baseball  
invites you to attend our  
**1<sup>st</sup> Annual**  
**Easter "Egg-Splosion" Hunt**

A FREE, fun event for people who are blind or visually impaired.  
Beeping eggs built by the Jackson Police Department's Bomb Unit will give individuals the opportunity to listen and hunt for the Easter eggs in exchange for candy-filled eggs.

**Saturday April 1, 2023**  
**10:00 AM – 4:00 PM**

**The Jackson Baseball Stadium**  
**4 Fun Place**  
**Jackson, TN 38305**

Registration Required

GAMES  
ACTIVITIES  
CONCESSIONS  
FOR SALE

### Lighthouse Guild Introduces New "Ask the TVI" Online Program

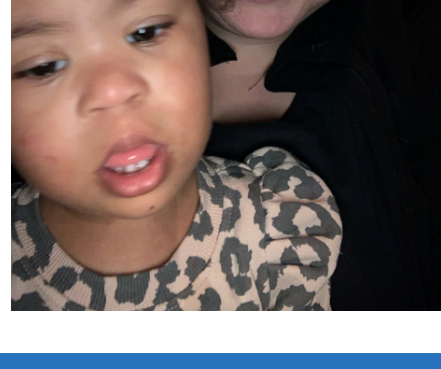
During Lighthouse Guild's new "Ask the TVI" online support group, being held the second Thursday of each month, a Teacher of the Visually Impaired (TVI) will provide information about children's vision loss, development, early intervention, educational policies, transitions, and more. Upcoming topics include: finding the right school for your family; transitions from early intervention to preschool; early intervention services; and development of vision, birth to age 5. Find out more and register below.



### BEST Family Feature

by Natalie Gilbert

When Marley finally came home, from being in the NICU for a month, our Developmental Therapist from BEST, Rachel, and her team went straight into work. The communication we had was more than what I could have ever asked for; from being flexible, to how developmental therapy works and what it is, giving tools to meet her goals, to Ms. Rachel feeling and being apart of our family. Now at two years of age she is our social butterfly that is so aware of the things around her. She's walking, talking, and even does her simple tasks of throwing away trash, cleaning up her toys, to even helping out somewhat with her little brother. Having early intervention through TEIS and BEST is such a relief because as a first time parent, you already don't know where to start exactly, let alone with a child with disabilities. This program is amazing for any family and thank everyone who's had a hand in helping Marley grow up in the best way she knows how!



### WHAT WE'RE LOVING THIS MONTH!



In honor of Easter, this month we're featuring beeping Easter eggs, a favorite of families of children who are blind or visually impaired. These beeping eggs by Maxi-Aids can be used year after year with easily replaceable batteries.