



Miranda Diaz

Congenital CMV

A Parent's Perspective on Hearing Loss in
Children & EHDI Benefits



CMV Facts



#1

It is estimated that 50-80% of adults in the United States have been infected with CMV by the time they reach 40 years old.

#2

1 per every 200 children is born with congenital CMV in the United States, making it the most common congenital viral infection affecting newborns

#3

1 out of 5 babies with congenital CMV will have symptoms or long-term health problems

#4

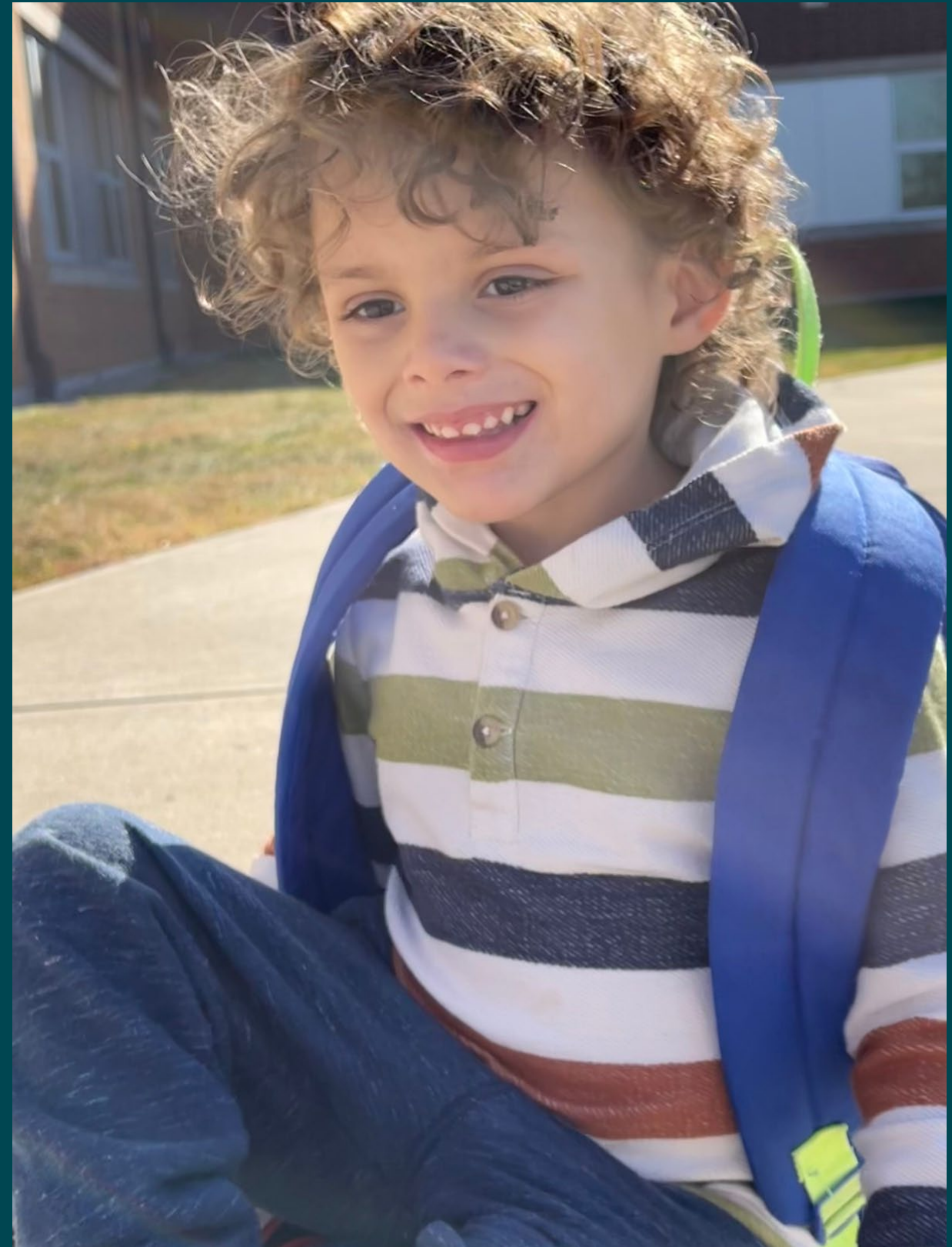
1 child is permanently disabled by congenital CMV every hour

#5

#1 non genetic cause of birth defects in infants/children



Greyson's Story



Diagnosis Timeline

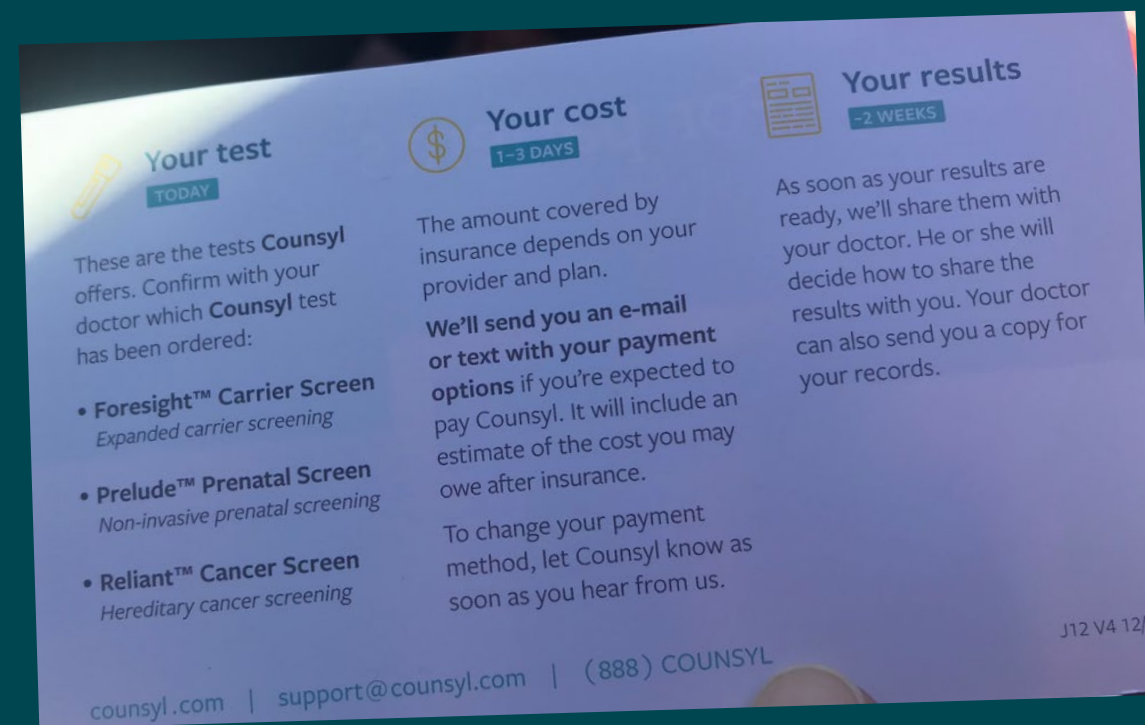


Mother's Day
May 13, 2018
***Surprise Gender Reveal**

18 Weeks
May 9, 2018
***Peek-A-Boo Scan**

May 14, 2018
***Call from OB office saying he was**
at high risk for Down Syndrome

20 Weeks-May 24, 2018
***OB gender scan and follow up on**
genetic testing




Diagnosis Timeline


May 31, 2018

*First MFM appointment, not DS but “textbook CMV”

June 14, 2018

*Results came back that I tested positive for a recent CMV infection

!  **CYTOMEGALOVIRUS Ab IgG**
5/31/2018
Dr. Quinn C. Davis, MD >

!  **CYTOMEGALOVIRUS Ab IgM**
5/31/2018 >



RESULTS

CMV IgM

Value **2.3**

Standard Range <0.9

Reference Range:

<0.9 Non Reactive
0.9 to 1.0 Indeterminate
>1.0 Reactive

The absence of CMV antibodies suggests that the patient has not been exposed to the virus and is susceptible to primary infection.

The presence of CMV IgM antibodies is indicative of recent exposure to the virus.

Our Next Steps

- Bi-Weekly/Weekly MFM Appointments
- Fetal Cardiologist
- Infectious Disease
- Nephrologist
- Neurologist
- Weekly NST

Greyson's Arrival



RESULTS

Cytomegalovirus
Quant. PCR

Value **Detected**

CMV Source

Value **.URINE**

Started Antivirals on Day 3

⚠ Culture

Value **POSITIVE for
Cytomegalovirus at day 1**

Greyson's Medical Journey



Head Ultrasounds &
MRIs



Hearing Tests &
ABRs



EEGs

Greyson's Medical Journey



Head Ultrasounds & MRIs

Hearing Tests & ABRs

EEGs

Echocardiogram

High Blood Pressure Monitoring

Feeding Therapies

Monthly Blood Draws

Early Intervention

Behavioral Therapy

Speech Therapy

Physical Therapy

Greyson's Medical Journey



Cerebral Ventricuomegaly

Microcephaly

Calcifications in Brain

Hypertension

Developmental Delays

Epilepsy

Sensorineural Hearing Loss

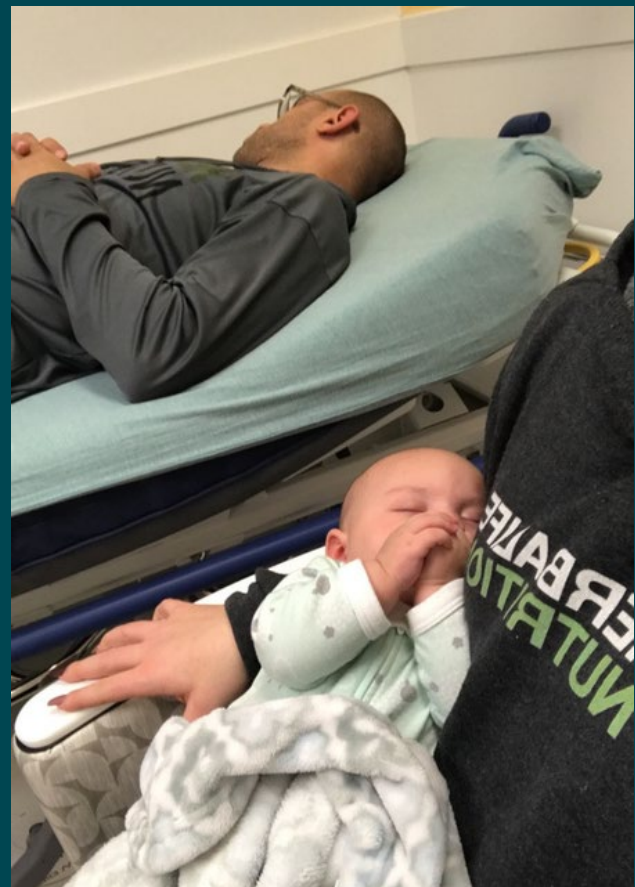
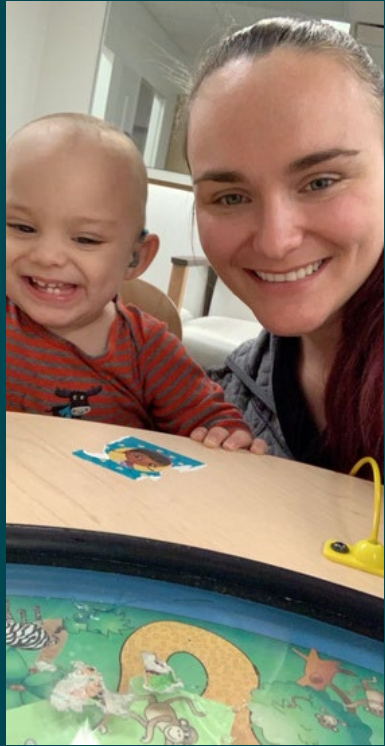
Mild Cerebral Palsy

Proprioceptive Sensory

Disorder

Feeding Issues

Behavioral Issues

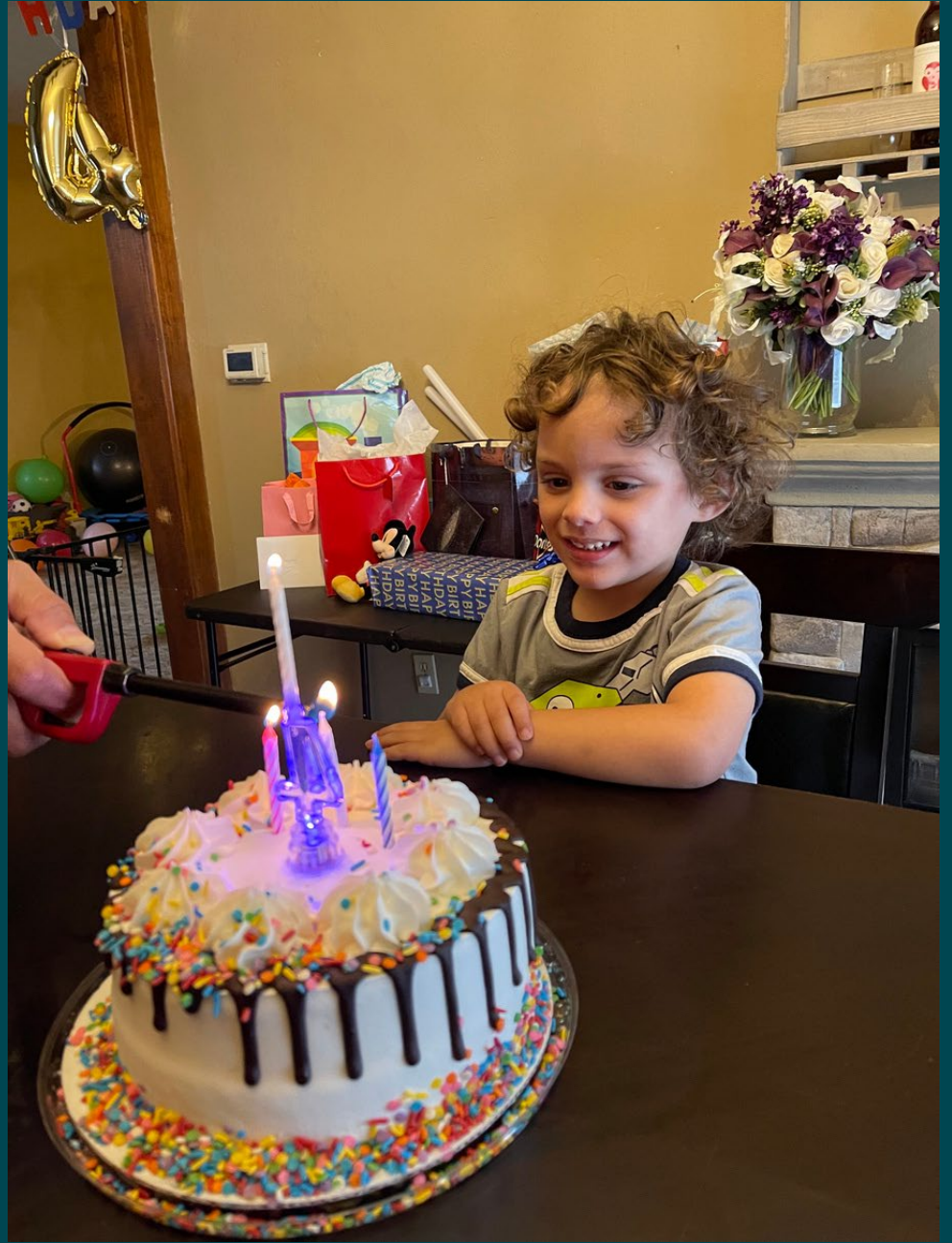


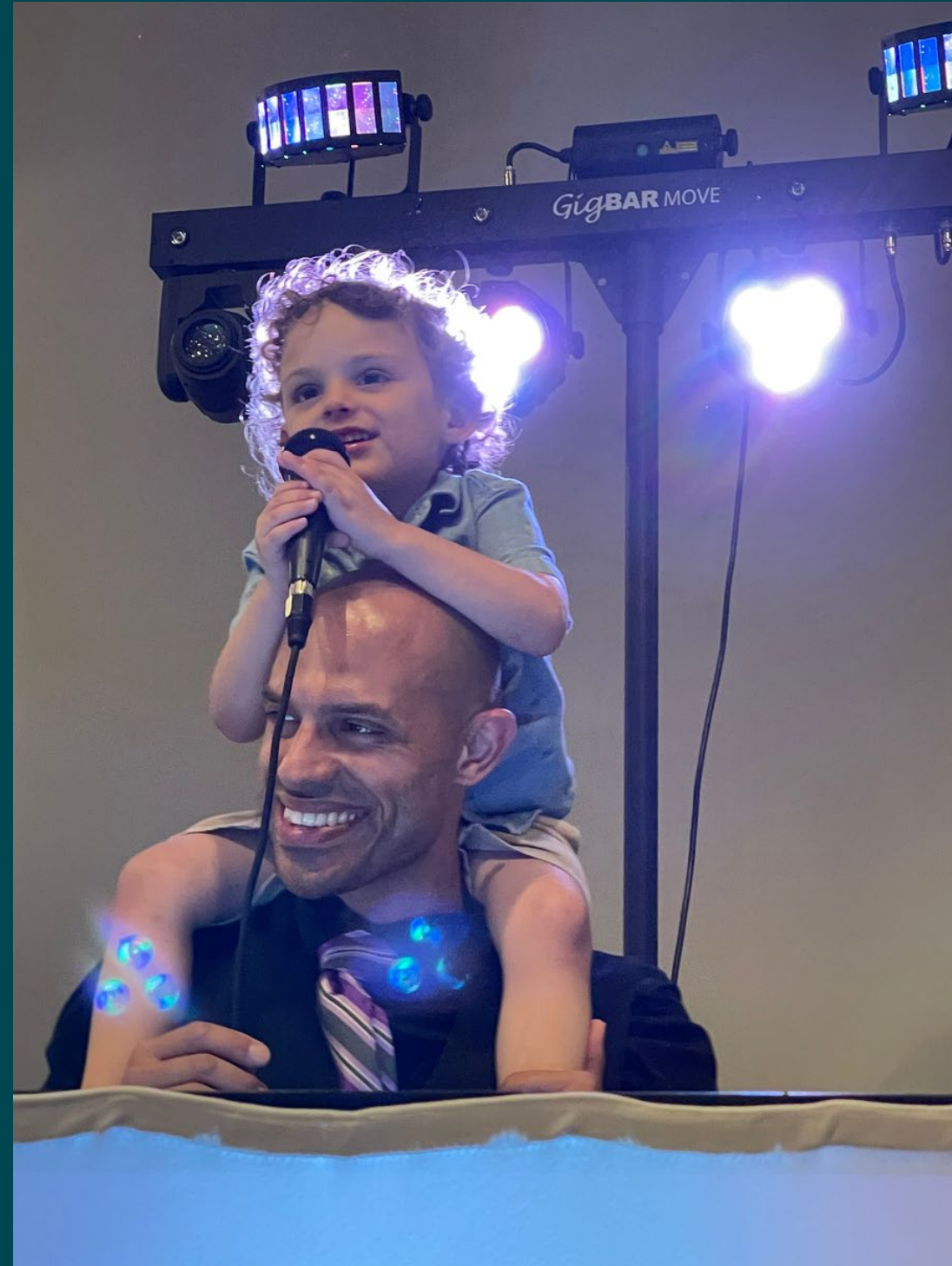


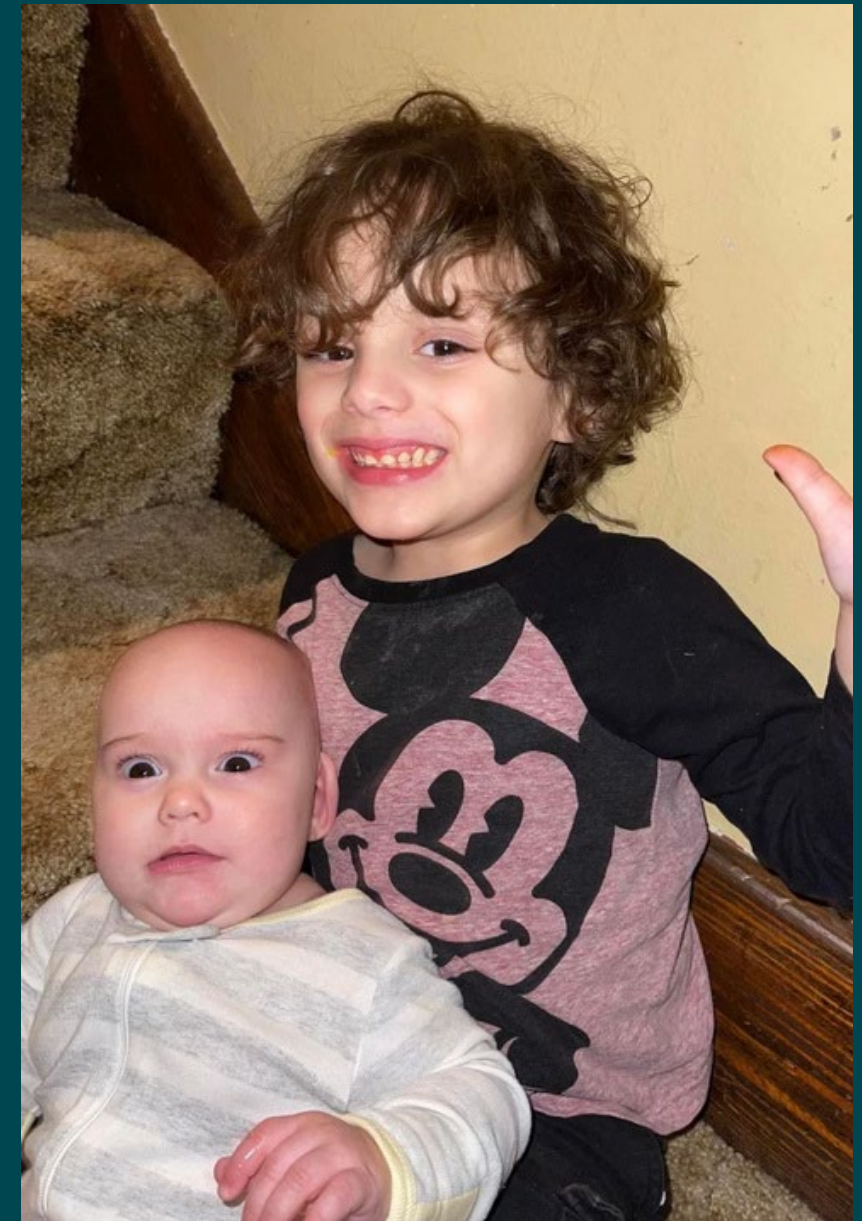
4 Months Old













How To Help

- Educate (Don't Be Afraid)
- Provide ORGANIZED Resources
- Providing Contact Points
 - Groups
 - Specialists
 - OTHER PARENTS
- Listen To Those Advocating For Their Children
- Reassure Them They Are Doing A Good Job

Contact Information

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