



Bella Dawn

"A Beautiful Beginning"



Bella's Beginning

- February 5, 2017
- Perfect pregnancy
- Symptoms at birth
- Life Flighted to the NICU
- Diagnosed on Day 3 - Cytomegalovirus



Complex Medical Issues

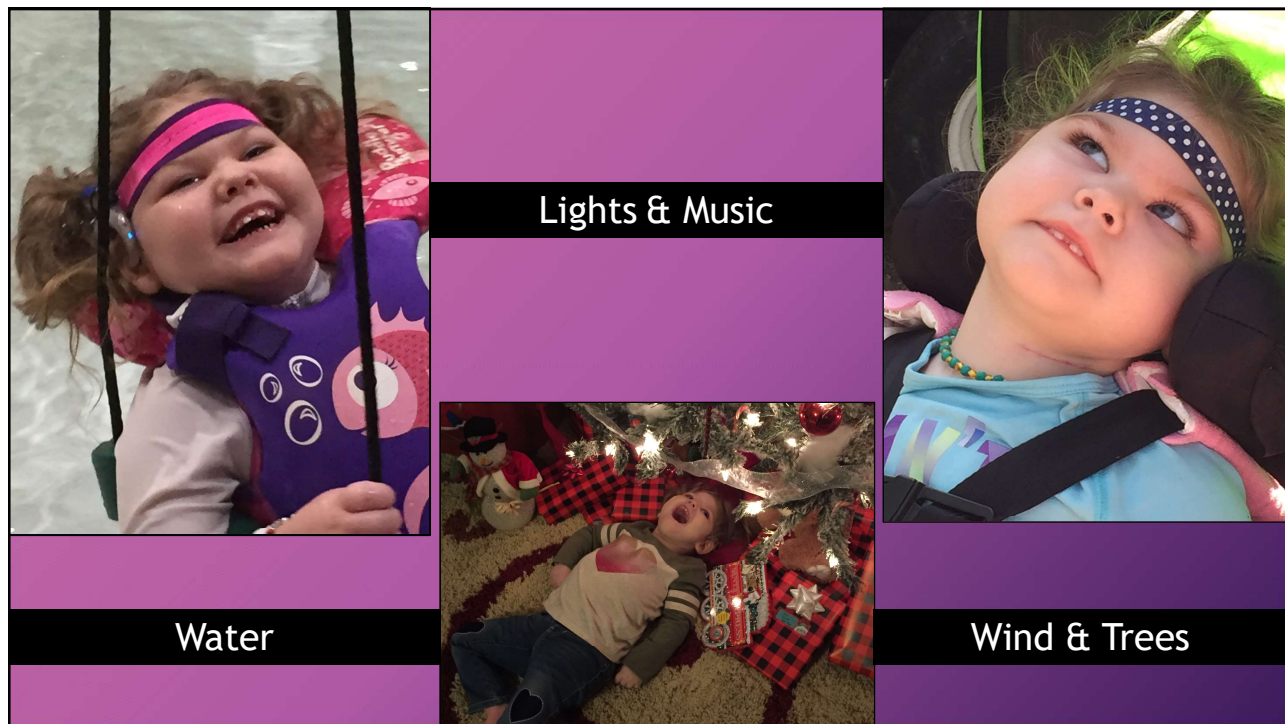
- Microcephaly
- Polymicrogyria
- Brain Calcifications
- Bilateral Sensorineural Hearing Loss
- Epilepsy/Infantile Spasms
- Lennox-Gastaut Syndrome
- Cortical Vision Impairment
- Cerebral Palsy
- Respiratory Failure
- Gastro Complications
- Autonomic Dysfunctioning



Who was Bella?

- Twinkling Blue Eyes
- Most Infectious Laugh
- Super Nosy
- Magnetic Personality





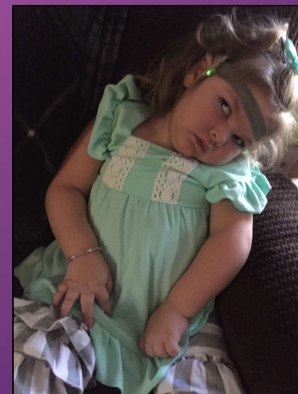
Strong Personality

- Opinionated
- Determined
- Persistent



"Bella didn't need words in order to communicate her desires!"

"Everything had to be Bella's way!"



Family 2019

Bella loved her brothers and her sister!

Matthew, age 19
Zachary, age 15
Timothy, age 13
Jackson, age 12
Mady, age 10
Ben, age 8



Bella's Struggles

- Increasing seizure activity
- Need for more and more medication
- Automimic Dysfunctioning Increased
- Digestive issues
- Respiratory issues
- Four Surgical Procedures



Feb 2018-June 2018
Hospitalized



"We didn't know what would kill her first, her complex medical conditions or all the strong medications she had to take."

Bella's Butterflies



- Educate others about cCMV
- Advocate for Bella's Bill 4 CMV
- Create a Community for cCMV Families
- Share Bella's Story
- Do the Things She Loved



Rowan, 4 months (Lexington, KY)

Rowan's mother had a toddler at home during her pregnancy. She was never told not to share a spoon, eat after, or drink after her toddler, in order to protect from cCMV.



Kaylin, 25 (Lewisburg, KY)

Kaylin's mother worked as a CNA in 1996, during a viral outbreak. She describes it as being much like conditions with Covid 19. However, she did not know the virus was Cytomegalovirus until she began experiencing pregnancy complications and her unborn daughter was diagnosed with cCMV.



June, 6 (Louisville, KY)

June was not diagnosed at birth despite having symptoms. She was not diagnosed two months later when she failed her hearing test. Not even when she was sick and began having infantile spasms. June's mother took her to another doctor seeking answers and a diagnosis of cCMV was given at 3 months old.



Cameron, 6 (Richmond, KY)

"This situation could have been avoided," said his mother. If only there was more education and newborn screening. Cameron's father contracted CMV during the pregnancy, but their OB/GYN did not show concern. Cameron was not tested even at birth, despite having symptoms.



Destany, 5 (Harrodsburg, KY)

"As a nurse, it is frustrating to me that no one ever warned or educated me about CMV, and we only learned about it very briefly in both the practical nursing and registered nursing programs I graduated from." Destany was another child not diagnosed at birth and who missed out on early interventions due to the lack of identification.

George, Forever 2 (Maysville, KY)

George's family were forced to relocate after his diagnosis. George needed a lot of daily care and was in and out of hospitals a lot. The family needed to be closer to extended family in order to have more support.



cCMV in KY

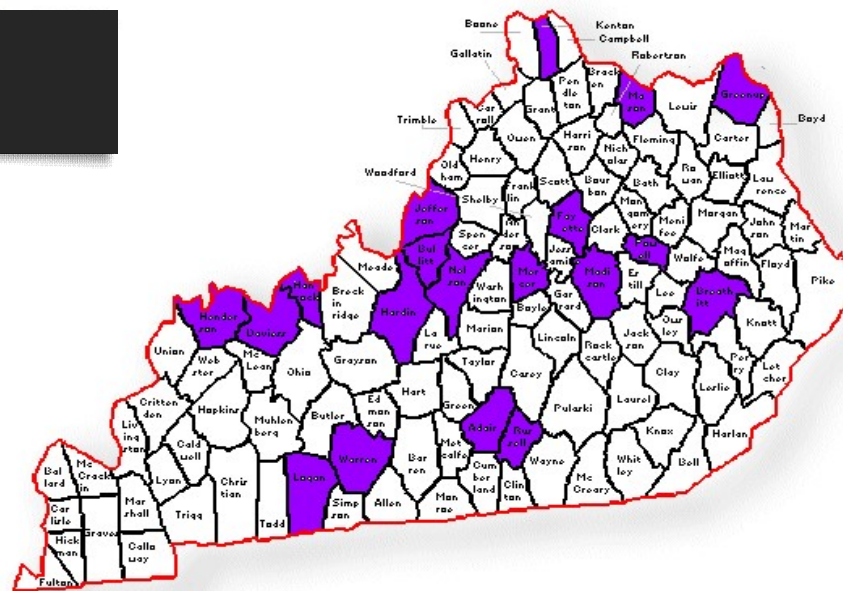
Current Map

- 39 Families
- 19 Counties
- 7 Deaths

Survey 30 Families

- 40% Diagnosed by 3 weeks
- 42% Antivirals at Birth
- Half on Kentucky Medicaid

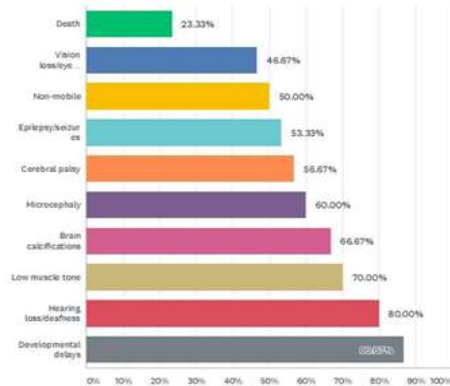
cCMV Families



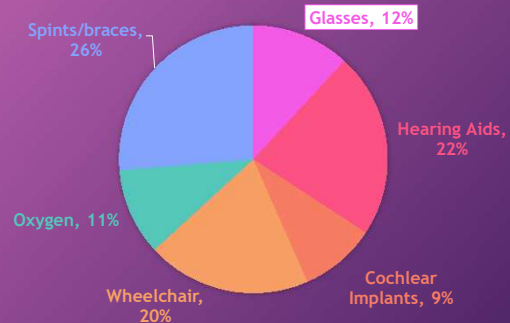
Cost of cCMV

Health conditions caused by cCMV

Answered: 30 Skipped: 0



SPECIAL EQUIPMENT



Individual Cost of cCMV

Hospital Stay	\$400,000 (100 days)	Respiratory Vest	\$15,000
Medication	\$207,784 (3 years)	Wheelchair/stroller	\$12,000
Cochlear Implants	\$200,000 (2 pair)	Specialty Bed	\$8,000
PICU Stays	\$84,000 (14 days)	Cough Assist Machine	\$7,500
Life Flight	\$24,000 (2 times)	Floor Sitter	\$3,000
VNS Implant	\$25,000	Stander	\$3,000
Handicap Vehicle	\$22,000	Oxygen	\$2,000

* These costs represent average cost to one family and this is not a complete list.