

## Newsletter

# September 2023

#### Next Event: Family Fun Night



### 3 x 3 Basketball Tournament held June 17th

The action was fast, furious, and fun at the annual three-on-three basketball tournament fundraiser for FFCT on Saturday, June 17<sup>th</sup>. We appreciate all those who came out to participate or to cheer for their favorites.



Pictured above are the adult division winners, with their shirts, L to R: Jonathan Orr, Teren Bingham, Spencer Stevens, and Preston Merrill. Below are the champions in the youth division.



Did you know?

All FFCT funds stay right here in our area to help local families.



#### In the Works:



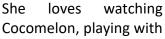


## Featured Warriors: Ella Morales



Ella Morales has a twin brother, as well as an older brother and two older sisters. Born with chromosome 3p depletion, a very rare genetic disorder, she spent the first month of her life in the NICU at Phoenix Children's Hospital and is no stranger to surgeries.

Ella turned four years old at the end of July, and is currently in her second year of preschool. She has taken some steps and is expected to be able to move about on her own with a posterior walker before long. Right now she is thriving! She just had a surgery which, along with her hearing aids, has her hearing pretty well. She has various therapies every week and sees a lot of specialists at Phoenix Children's: audiology, cardiology, neurology, GI, ENT, etc.





her siblings, and she loves music, especially anything that lights up and plays music. She is a happy, sweet, loving little girl and her family adores her They are very thankful to have help from our own community through Families Fighting Cancer Together. Her mom, Erika, says, "FFCT has really helped, especially for all the trips to Phoenix Children's Hospital. It has made a big difference for our family as we have to travel there so frequently and gas is so expensive!"









#### **Brielyn Brown**

After raising their first two children, Brielyn's parents decided to adopt First came her sister, Londyn, from China, who had a congenital heart defect that required surgery. Brielyn came into the family as a foster baby, and eventually they were able to adopt her. She came as a foster baby, along with a heart monitor, when she was one month old and weighed only six pounds. At the time, she had seizures in addition to her heart condition.

When Brielyn was 10 months old she went into cardiac arrest. You can read the dramatic story here: <a href="https://gilavalleycentral.net/quick-action-by-safford-police-saves-babys-life/">https://gilavalleycentral.net/quick-action-by-safford-police-saves-babys-life/</a>





She needed a heart transplant, but wasn't a candidate. She spent her first birthday in the ICU on 18 different medications. She doesn't respond to medications well. She couldn't drink from a bottle and had to have a feeding tube. Her family took her to California (UCLA Neurology) in hopes of getting help, and they did MRI and PET scans, EEG and have been able to help her. They still make trips for treatment. Brielyn loves the plane ride.

Brielyn has cardiac rhabdomyoma, a benign tumor in the muscle of the heart—hers is right down the center of the heart and is inoperable. It was supposed to go away on its own but hasn't. She's been diagnosed with tuberous sclerosis complex, a rare genetic disease that causes non-cancerous tumors to grow in the brain and other areas of the body. Brielyn has tumors in her brain, her eyes, her kidneys, and her skin.

Londyn is now 11 and Brielyn is 6 and doing well. After years of not being able to swallow food, she now can eat anything. However, the tumors in her brain cause epilepsy. The sad thing is that when she is really happy, the extra adrenaline that is released causes seizures. That is her biggest problem right now.

She loves Mickey Mouse and anything Disney. In November they went to Disneyland and she got to see Santa and the Christmas decorations. Her mom says she is their "extra extra" child, meaning she wants the fastest, biggest rides. She loves dancing and music. She carries a tune well even though she can't articulate words. She loves to play with doll houses and loves all her therapists.





