ECFVOICE FOUNDATION



Happy 40th! Thank you for 40 years of kind support!

# BRAEDEN: AN OLD SOUL

#### **EVERYONE WHO MEETS BRAEDEN CALLS HIM AN OLD SOUL.** "He was always mature for his age," his mom says, "but this year he learned to grow up even faster."

In May of 2022, Braeden began holding his arm folded against his body during soccer games. An orthopedist took x-rays and found no apparent injury. The next month, the school nurse noted a slight foot drop when he walked. An MRI confirmed his family's worst fear: brain cancer.



Surgery could only remove part of the tumor. It also caused a stroke that kept Braeden in the hospital for a month and left him with limited use of his arm and leg. After a long inpatient rehab relearning how to walk, Braeden began chemotherapy to shrink his tumor.

He got so sick from his first treatment he couldn't keep anything down for three days. He had to have weekly blood tests and received three platelet transfusions. This left Braeden mostly confined to the house, or back and forth to the hospital for tests, bloodwork, and doctor appointments.

"ECF was a lifesaver for our family," says Braeden's mom Kathleen. Caseworker Dina provided emotional support for the whole family--Braeden who was upset that he couldn't live a normal life like his friends at school, his two younger siblings who struggled to understand what their brother was going through, and his parents who were overwhelmed with fear and anxiety.

•• Miss Dina became like family to our children and us. We are able to express our feelings to her and feel completely comfortable while doing it. ??

Braeden's parents saw him struggling with the chemo regimen both physically and mentally. Though they were told that was the only treatment option, they decided to seek other opinions. Finally, one neurosurgeon in Tennessee said he believed that he could get most, if not all, of the tumor out with surgery. Braeden told his parents that he felt good about this surgery, and he knew it was the right choice for him. He was right! The surgery successfully removed the whole tumor without complications.

Braeden still has a long road ahead as he will require ongoing scans and monitoring as well as extensive outpatient rehab, including PT and OT to deal with the lasting effects of the stroke. His mom says he captured the hearts of all his therapists!

Thanks to a wonderful donor to ECF, Braeden was able to get two special braces—not covered by insurance-- for his leg and arm that continuously stimulate his muscles so he can eventually regain the limb strength he had before surgery when he was great multi-sport athlete. Already he is able to ride rollercoasters and swim in the ocean. He is also enjoying new hobbies including horseback riding and pickle ball, and has also returned to the golf course as an honorary member of the Princeton University Golf Team.

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### **AVA:** In Her Mother's Words



WE GOT THE CANCER DIAGNOSIS ON FEBRUARY 26, 2019. Ava was actually a little relieved to finally have an answer to why she had been feeling so "weird " --heart racing, light headed, very low energy and very, very pale. We were told over and over it was anxiety, but we both knew it was more. But we had no clue what Ava would go through.

We found out she had a rare leukemia and had to be transferred to Children's Hospital of Philadelphia for treatment. Ava had every side effect you could have. She couldn't walk after her first month of chemo because the steroids had depleted all the muscle in her legs. She was hospitalized for methotrexate toxicity, constipation, mouth sores, butt sores, fevers, puking, getting down to 90 pounds, having a feeding tube, losing her hair not once but twice. She also had physical therapy for the neuropathy in her feet and two shoulder surgeries due to bone deterioration from the steroids. When I say my daughter has literally been through hell and back, she has.

I still wonder why this happened to her. A beautiful 13 year old dancing six days a week, getting into a dance academy, enjoying 8th grade and then BAM--gone! She would not have a "normal" life at all... and then add Covid into the mix.

After almost three years, Ava finally finished her treatment and has been off of chemo almost two years! We still go for checks ups every three months. She talks to a therapist once a week to help with anxiety and PTSD.

Now 18, Ava decided to go to school to be a pediatric oncology nurse. She loved her nurses and had learned that a couple of them were once treated at the same hospital, and it made such a difference! She is attending Drexel University's nursing program! She is thriving!!!! She made it!!!

If anything good came out of any of this, it is that she will become that nurse who can share with a patient her story of having cancer and let them know she knows what they are going through.

### **EMMA:** STRIVING TO THRIVE



#### IN JULY 2018, SEVEN-YEAR-OLD EMMA STARTED FALLING FOR NO REASON. She would bump into people walking toward her, unable to move to get out of their way.

Her doctor ran some tests and suspected a brain tumor, which was confirmed by a CAT scan. But the family had no clue yet that it was cancer and no idea what ordeal was about to start.

Her first surgery lasted 14 hours. The doctors said she might come out impaired. Though she came out OK, she had to have a second surgery to remove the rest of the large tumor that was spreading toward her spine. Emma's mom said she still wasn't told it was cancer, but knew

because of the way the doctors looked at her. Fortunately, they were able to remove the whole tumor. Unfortunately, Emma emerged from the second surgery unable to move or talk. She couldn't eat. She tried to scream in frustration but no sound came out.

Emma began what would be many months of speech therapy, physical therapy and occupational therapy. She also endured 6 weeks of chemo and radiation. Though Emma was initially upset about losing her long hair, she ended up liking her new short look. Her mom cut her own hair short in solidarity with her daughter.

Emma and her mom met ECF toward the end of treatment. Emma's mom had to stop working because of all the treatment and therapy appointments, and she was struggling to handle the stress and financial challenges. ECF Caseworker Erin stepped in to provide comfort and serve as a sounding board. Because of the



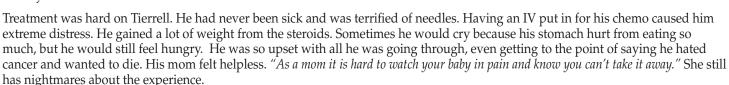
pandemic, Erin couldn't visit in person but called the family every week, played games with Emma on video calls, set them up with monthly grocery deliveries and helped pay mounting household bills. Erin also connected Emma with other ECF kids. Emma became close with Gianna and Avery, while Emma's mom and Avery's mom became best friends. She calls them her *"angels on earth."* 

Emma is doing well now but has memory issues, thyroid problems and difficulty breathing. She uses a wheelchair most of the time, but can stand for longer periods and walk a few steps. Emma loves watching movies and browsing at Five Below and Target. She likes to help her mom in the kitchen even though she has difficulty with fine motor skills and breaks a lot of cups. Her mom tells her "*don't worry; this is how we learn.*"

Her favorite place to be is in the pool, because she can move and feel free there like she used to on the soccer field. From an early age she followed her older siblings love for soccer. She longs to be able to play again. Emma says, *"I just want to run and run and run so fast until I fall."* 

# "IT'S HARD TO WATCH YOUR BABY IN PAIN"

**IERRELL** was diagnosed with cancer the summer of 2020 when he was nine years old. He woke up in the middle of the night complaining of back pain. Though he was able to walk into the ER, after a few hours he was bedridden. When told it was leukemia, his mom Tierra felt *"as if I was punched and all the wind left my body."* She says they were *"thrust into a world we knew NOTHING about."* Both of them were terribly afraid.





"God was the only way we were able to get though," Tierra says. She calls ECF "the blessing we knew we needed but didn't know how to find." She says ECF Caseworker Darlene treats them like her extended family. She gave the family gift cards for groceries and gas and provided them with school supplies and birthday, Easter and Christmas gifts. Tierra and Tierrell have also spoken at several ECF events, moving their guests to tears with the story of their cancer ordeal.

Throughout everything, Tierra was dealing with her own health problems. The single mom is a double amputee in renal failure, on dialysis and in need of a kidney. This summer, she was due to get her Bachelor's Degree but wasn't able to finish because of three abdominal surgeries over 7 weeks. *"I want to finish school to show my son that no matter the obstacles, you can always overcome."* 

Fortunately, Tierrell is now in remission. The "shy but silly" 12-year-old loves video games,

swimming, eating at nice restaurants, laughing and, most of all, his mom and his aunts. His experiences have given him wisdom he wants to share with other kids going through cancer. *"Cancer is scary and sometimes you don't want to deal with all the pain,"* he says. *"But don't give up. Your mommy and daddy will support you all the way. Talk to them about your feelings. Don't be afraid of their reaction. They love you and care for you."* 



## **ISABELLA:** COVID Saved Her Life

### LAST NOVEMBER, TEN YEAR OLD ISABELLA GOT COVID. IT SAVED HER LIFE.

Isabella was having trouble breathing. An emergency room chest xray looking for damage from the virus revealed a tumor six inches in diameter spreading across her lung and heart. It turned out to be cancer.

Fortunately, the doctors were able to remove the tumor, and Isabella emerged from surgery with her lungs working fine. But her family's ordeal was just beginning. She had to have radiation for six weeks and months of chemo requiring 3 day hospital stays. She suffered all the side effects the doctors warned them about including nausea and hair loss. The multiple required injections were harrowing for Isabella who has always been terrified of shots. Everyday her dad had to drive many miles to get her to treatment so had to take time off from his police officer job. But he says he "can't complain because she was the one who went through it all."

But they didn't go through it alone. ECF helped them with food deliveries and covering unpaid bills that were piling up. Their ECF caseworker ViAnna also became like a big sister to Isabella. Her dad says Isabella doesn't talk to a lot of people, not even her cousins or other family members. But within 15 minutes of meeting ViAnna, they were talking like old friends. They immediately developed a special bond that continues to this day.

Luckily, Isabella has been in remission since May. Having missed an entire year of school, as soon as she felt better she wanted to go back. Her school let her return for the final three weeks of the year. She even got to play the last two games of season with her beloved soccer team, whose coach encouraged Isabella's teammates to stay in touch with her while she was in treatment.

Her dad says she is appreciating life differently now, taking chances, inviting adventure and *"taking everything in."* She even tried cliff diving during a camping trip this summer, something she previously said she would never do. *"She has taught me so much about life,"* her dad says. Isabella would comfort HIM when he was sad about her cancer. *"She doesn't let cancer define her; she defined IT."* 

# upcoming —— EVENTS

#### NORTHERN REGION GOLF OUTING September 29, 2023

BOCCE TOURNAMENT

October 1, 2023 SOUTHERN REGION GOLF

OUTING

October 16, 2023

ECF FAMILY HOLIDAY PARTIES December 2023

CRYSTAL GALA March 2, 2024

#### ECF IS GRATEFUL TO THE FOLLOWING FOUNDATIONS AND CORPORATIONS THAT PROVIDED RECENT GRANT SUPPORT:

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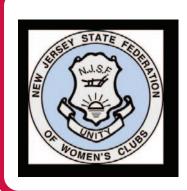
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### **BRAEDEN:** AN OLD SOUL



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Despite missing school for most of last year, he kept up his studies through home instruction and still made the High Honor Roll. He is very excited to start 7th grade and go to school full time. "We know he will do great *things one day,"* his mom says. "In fact, he has decided he would like to become a brain surgeon so *he can help other children* like him. If anyone can do it, we know Braeden can!"



We love the NJ State Federation of Women's Clubs! They continue to do amazing things for the families—donating backpacks and lunch boxes, running food drives and helping at events. Thank you!

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