ECFVOICE



THE NEWSLETTER OF THE EMMANUEL CANCER FOUNDATION

GIANNA: A Ball of Energy

GIANNA is the epitome of a fighter! Two years ago she left the hospital after her last chemo treatment. This year the energetic 8-year-old ran a 5K. She is amazing to say the least!

It all started in September 2019 in her second week of kindergarten. A slight limp in the morning that worsened by the end of the day sent Gianna and her mom Jennifer to the ER. They found a packed waiting room; the hospital computer system had shut down. They decided to leave and come back the next day, but by the time they got to the door,



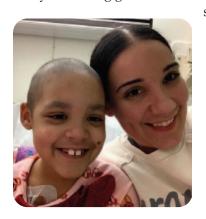
Gianna grabbed her mom's hand and said, "No, my leg!" While waiting for their turn, mom took photos and videos of Gianna's legs to amuse her daughter and pass the time. They didn't realize it was the start of documenting her cancer journey.

Jennifer was shocked to learn the mass found on Gianna's leg was cancer. Gianna immediately had a biopsy and started treatment a few weeks later. What followed was two month-long cycles of the strongest chemo available. Jennifer was distraught. But Gianna was stoic, only worrying about her mother's feelings. On the ride home from the biopsy, her mom was crying and Gianna told her to pull over. "Listen, you heard terrible news," she said. "But I will be OK, don't worry."

A week after her 6th birthday, the doctors performed a rotation plasty, a surgery to amputate the middle part of the leg and then reattach the lower section backwards. The ankle serves as a replacement knee joint, allowing greater function. Gianna herself chose to have this type of surgery after consulting with her older brothers, who she adores.

She said, "If I can dance, then OK!" Gianna would have to learn to walk again using a prosthetic leg and foot.

Then the pandemic hit. The arrival of her prosthetic was delayed. Her leg got weaker without use. At night she



started fretting about her treatment, about losing her hair, about how she would ever walk again. "Can I get my leg back?" she asked. When the prosthetic finally arrived, she at first refused to wear it. She felt embarrassed and scared. Then she had a meeting with her surgeon, with whom she has a close bond.

She came home from that talk, put on her leg and never took it off. She just ran a 5K with her surgeon!

Her mom calls Gianna "a ball of energy." She loves playing baseball, riding her bike, trying on makeup, dancing and singing. When she grows up, she wants to be a Child Life Specialist, inspired by those who helped her in the hospital. She is comfortable with her prosthetic now, even taking it off to show classmates how it works.

Jennifer calls ECF "a blessing," helping her through the difficult and lonely journey of being a parent to a child with cancer. There is no cure for Gianna's cancer, and she won't be considered cancer free until three more years of clear scans. "Every fall is a trigger, every limp," Jennifer says. "Our caseworker Dina is so supportive and nice and there for me when I'm having a hard day and always makes time for me." Gianna, too, has been worrying more, experiencing anxiety before every scan. "Cancer is not over," her mom says. "People come and go but ECF is always there for us."

MEET TONY IN HIS OWN WORDS

(speech from ECF's 2022 Crystal Gala)

MY NAME IS TONY SALERNO. I am a recent graduate of Holmdel High School, a freshman at Brookdale Community College, and oh yeah... a three-time cancer survivor. My cancer journey is a long one... let me try to recap it in 500 words or less.

When I was just 2 ½ years old, I was diagnosed with stage IV high risk neuroblastoma. I went through five rounds of chemotherapy, spot radiation, total body radiation and two stem cell transplants. Good news is, I beat the cancer... but the bad news was that it came at a pretty high cost.

In the years that followed, I developed cataracts, diminished thyroid function, high frequency hearing loss, and I had to have pins put in my hips. When I turned 13, I went into kidney failure. My father was nice enough to give me one of his. He tells everyone it wasn't a problem—he had an extra.

Following the transplant, I developed a secondary cancer called PTLD. I had to go through chemo again. Four days after my last chemo treatment, I woke up in the middle of the night in excruciating pain. My parents called for an ambulance. It wound up that I had perforated my bowel. I was rushed to Children's Hospital of Philadelphia in pretty bad shape. As a matter of fact, they only gave me a 5% chance of survival. I was placed in a medically induced coma for five weeks while they tried to clear the sepsis and the damage it did to my body. When the doctors lifted the paralytic, I was actually paralyzed. All I could do was blink my eyes.

They said I developed critical illness myopathy where all the connections between my brain and muscles disappeared overnight. I spent eight straight months in the hospital and the last three years doing physical therapy to regain strength and mobility. It hasn't been easy, but I didn't give up.

Not only didn't I give up, but I kept up with my school work, after school activities and boy scouts. Not to brag, but I did

graduate with distinguished honors this past June, on time with the rest of my friends. I was a member of the National Honor Society and Peer Leaders, and I achieved the rank of Eagle with my Boy Scout troop. Like I said, I am just starting at Brookdale and plan to study TV and film production. You never know; maybe one day I'll direct and produce my own autobiography. So there's my story in a nutshell... and it only took me 382 words!!



Now that you have gotten to know a little bit about me, let me tell you a little bit about my family and the Emmanuel Cancer Foundation. After my initial treatment was over, my family knew we wanted to find a way to give back to the community that helped us so much. We give back by helping charities like ECF. I know from experience that families can't go through cancer treatment alone. It is stressful and isolating. That's where an organization like ECF comes in. Knowing that ECF can deliver food to a family's door every month, or birthday and holiday gifts for children and their siblings, or just having a trained social worker to speak with can make things for a family fighting cancer so much easier. The support they can offer is immeasurable and so needed. Smiles, happiness, and less stress are all things that doctors usually order.

So as long as folks like you continue to support the mission of ECF and until the researchers find cures, ECF will continue to be there to give support to kids like me.

IN MEMORY OF FATHER JACK EGAN: With ECF from the Beginning

In honor of ECF's upcoming 40th anniversary in 2023, we'd like to remember Father Jack Egan, who was instrumental in the founding of ECF. He passed away during Easter week 2022.

Father Egan was a close friend of Sue and Joe Vizzoni, who started ECF in 1983 after the death of their son Emmanuel. Father Egan was the priest at Manny's school and became involved in helping the family. Father Egan visited the Vizzonis often to comfort the family during their grief. Together they developed ECF based on the idea of providing other families the emotional and practical support Father Egan offered the Vizzonis. "We asked Jack to help us set up a program to do what he had done for us, all his small gestures of kindness and care that made a huge and vital difference for us getting through difficulty."

In addition to being a priest, Egan worked for many years as a social worker and with Catholic Charities. "He was one of the most spiritual people I've ever met," said Sue. ECF remains humbled and grateful to Father Egan for helping launch the organization, which carries on the same mission 40 years later.

CONGRATS TO THE 2022 WINNERS OF ECF'S NEW SCHOLARSHIP AWARD: WILLIAM AND ABIGAIL





We wish them the best of luck in college! Thank YOU for making this possible.



FIGHTING CANCER WITH A SMILE

Sophia's mom calls her "one energetic ball of sass" and dubs her the "happiest kiddo you will ever meet!" You wouldn't know from her bubbly personality and utterly adorable smile all that she has been through over the past two years.

After 6 months of migraines and several ER and pediatrician trips with no answers, a pediatric ophthalmologist discovered Sophia had no vision in her right eye. An MRI showed that Sophia had an aggressive brain tumor that spread to the lining of her brain and spine.

Sophia endured a year of chemo that failed to halt her tumor growth. Her doctors then put her on inhibitor drugs in hopes shrinking the tumor, but they caused painful side effects, including severe nail bed infections and ingrown toenails. This summer, Sophia's medical team stopped the treatment to give her body an

opportunity to heal in hopes she will have a better and more comfortable response to treatment, which resumed this month.

Emotionally, Sophia has handled it all really well. "She often says she wishes she didn't have to go to the hospital," says her mom, "but she is grateful for the friends she's made throughout."

Continued on page 4



HENRY: I FEEL BLESSED FOR THE PEOPLE WHO HAVE BEEN THERE FOR ME

My name is henry and I am the only child of my parents robert and

CHRISTINE. I was born in New York City on July 7, 2011. Just before my seventh birthday my family moved to Mahwah New Jersey where we now live with our two dogs Lola and Wally and two guinea pigs, Chips Ahoy and Sulis, named after my oncologist Dr. Maria Luisa Sulis.

In the months before my eighth birthday in 2019, I was feeling sick and very tired all the time. My parents took me one afternoon to meet my pediatrician at Memorial Sloane Kettering in New York City. I didn't really know what was going on until I looked up at the television screen in my room and it said Memorial Sloane Kettering Cancer Center. That's when I asked my parents if what I had was cancer, and they said yes.



What I have is called leukemia, the T-cell type. During the first month of treatment I remember feeling really tired all the time and really hungry. Since I was mostly confused about what was happening, I was afraid of the needles and all the different ways I was receiving treatment. I was definitely afraid about losing my hair. When it did, I really didn't like it but I also realized that it wasn't that bad because it was temporary. There were so many things happening that were new and strange and kind of scary. The form of escape that really helped me was watching lots of Harry Potter movies and also the movie *Miss Peregrines Home for Peculiar Children*. It allowed me to focus on something besides what I was experiencing.



When I grow up I hope to be an actor. I am also an animal lover, and I love watching shows about animals and veterinary surgery. My personality is that I am very social, and I love to play fun jokes on people. Just silly kinds of things that make people laugh. I love to swim, paddleboard and kayak, and this summer I got into fishing and reptile hunting. I love to play video games with my dad. I'm a big fan of all things Marvel and our whole family watched all of the Marvel Avengers movies during the pandemic.

Now that I am coming to the end of treatment soon, I'm still not sure what I will remember and take away with me. Some of the doctors and nurses and child life staff are people I will remember always, and I am very grateful for them. I'm also very grateful to ECF for helping to make things lighter and happier and a little easier through this whole experience. They are always sending little notes and cards and gifts, and I know they help my mom and dad. They also got me into a really fun experience which was being the Bergen County Police Chief for a day! That was one of the most fun things I've done in a while. I am super grateful for all they have done and so glad that other kids who have to have this experience can get help from ECF.

If I could speak to other children at the beginning of their treatment I would tell them they should be prepared that they're going to be very nauseous and not feel well and they need to try to stay strong by leaning on their parents and their family

and friends. I learned that in a crisis the people who stick with you are probably the people that you will have with you for the rest of your life. Some other people fall away from your life and that's OK too. I feel blessed for the people who have been and continue to be there for me.

upcoming EVENTS

ECF FAMILY HOLIDAY PARTIES
December 2022

CRYSTAL GALA February 25, 2023

2 MILE WALK April 2023

CORNHOLE TOURNAMENT May 2023

ECF CHARITY BASH June 14, 2023

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

Bastazo, Inc

Clock Tower Foundation

Eisai. Inc.

Fanwood-Scotch Plains Service League, Inc.

Foundation@ Cross River

Holmdel Fire Company

Merck Company Foundation

MSO, Inc.

Northfield Bank

Plymouth Rock Management Company of New Jersey

Preferred Home Health Care

St. Mary's Advocates, Inc.

 $The\ Grand\ Lodge\ of\ NJ,\ Independent\ Order\ of\ Odd\ Fellows$

Westfield Rotary Club Foundation, Inc.

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FIGHTING CANCER WITH A SMILE

continued from page 3



A family friend recommended that they reach out to ECF early in Sophia's diagnosis. "Caseworker Dina has been wonderful," Sophia's mom says. "Dina checks in regularly, and ECF has provided gifts and gift cards that helped us greatly through the holidays."

Sophia loves animals, being outside, and going to the boardwalk. She wants to be a K9 Officer when she

grows up. She also loves taking mixed martial arts. She began right before her diagnosis, but had to pause due to covid and her treatment. Despite some left side weakness and severe neuropathy in her left leg, Sophia is back taking her beloved martial arts classes.

The family has coped by staying busy. "My goal is for Sophia and her older sister Isabella to not ONLY think of cancer when they look back on their childhood." They try to attend as many events as possible and do fun family activities. "We are just making as many wonderful memories as possible while staying optimistic." Sophia's mom says, "We like to say we are fighting cancer with a smile."



THANK YOU

to the NJ State
Federation of
Woman's Clubs
for donating
over 1,200 new
backpacks
filled with
school supplies
for ECF kids and
their siblings.

WE NOW ACCEPT DONATIONS OF



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It's easy and there are great tax benefits for you. Any amount makes a difference for kids with cancer and their families.

Thank you for your kindness.

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