ECFVOICE

THE NEWSLETTER OF THE EMMANUEL CANCER FOUNDATION





Gift of a heated bathroom changes everything for one girl with cancer

This is a story about a girl whose difficult life was made brighter because of a kind donor like you.

RIELLE is a sweet teenager who has battled a brain tumor since she was seven months old. She has endured 17 brain surgeries and 12 different types of chemotherapy. Her family adores her, as

does everyone who meets her. Her mom Laura is her biggest supporter and "best buddy," as Arielle calls her.

Arielle struggles with the side effects of both the cancer and the treatment. Because of the tumor, Arielle is legally blind and has other significant physical impediments that make movement difficult. Her body cannot regulate its temperature, so when she is sick she doesn't get a fever. After so many years, her mom Laura knows to watch for other signes of illness, such as fatigue and lethargy. She knows then that hospitalization is usually required to keep her daughter safe.

But none of this stops Arielle. She cruises around the house with the help of her trusted walker. She finds joy in everything, despite all she has endured.

66 You can't help but smile when you experience Arielle's infectious laugh. 99

Her positivity, warmth, and kindness are inspiring.

Unfortunately, the many years of treatment and lost work time for her mom has taken a financial toll on the Toms River family. Mom is not able to work outside of the home because Arielle needs continuous care. Her homemade chocolate business faltered over the past year due to Covid. It is a struggle for the family to pay their bills and create the safe home environment Arielle needs.

This is where a wonderful donor came in to change the daily lives of Arielle and her mom. His kindness helped pay urgent household bills, provided gift cards for food and household items; covered the monthly costs of their ECF caseworker, Dina, who gives the family vital emotional support; and paid for heating to be installed in their previously unheated bathroom. Arielle and her mom are beyond thrilled with their new, warm bathroom! Getting out of the shower is no longer an unsafe situation for Arielle with her body temperature regulation issues.

Unfortunately, recent scans showed that Arielle's tumor is growing. The doctors say there is only one type of chemo left to try, but it comes with the risk of serious side effects. Arielle and her mom continue to focus on enjoying each day. They are grateful to the kind people like you who make those days so much brighter. *Thank you!*



CREATING THE EMMANUEL CANCER FOUNDATION: FINDING MEANING

IN A LIFE CUT SHORT

BY SUE AND JOE VIZZONI AND THEIR DAUGHTER POLLY

OVER THE YEARS, Joe and I have been asked how we started the Emmanuel Cancer Foundation. I would like to share some thoughts about how our loss eventually inspired the idea of an organization named in honor of our son Emmanuel, whose name means "God with us."

THE EVOLUTION OF THE IDEA took a lot of reflection and help from so many caring people. We had no idea if the effort would take hold, how long it would last, or even what kind of services to offer. We asked our

dear friend, the priest/social worker Father Jack Egan, to help us set up a program to do what he had done for us—all his seemingly small gestures of kindness and care that made a huge and vital difference for us getting through difficulty. Joe and I were intimately involved with ECF for 15 years. Thirty-eight years later we remain humbled and grateful to Father Egan and all our dear friends and associates who helped us launch ECF, and to the many who carry on the mission today.

THE SIBLINGS LOVED EACH OTHER!

It takes a lot of wherewithal as a human being to move beyond questioning why a child

gets so very sick or leaves life too soon.

Guilt, reliving decisions, blaming oneself, or trying to blame whoever or whatever was responsible are all part of the grieving process. In our personal experience as a family, it sometimes felt like the ongoing events of life were relentless. Without the "small" but thoughtful acts of kindness from caring people, it would have been so much harder to reconnect with hope and discover the meaning that resides

within crisis and tragedy.

Just one example I want to tell you about is Manny's school bus driver. He and I worked out a system



MANNY AND HIS SISTER POLLY: JOE, SUE, MANNY AND POLLY

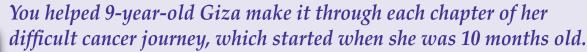
where if I left the porch light on, he knew Manny would be well enough to go to school that day. As the illness progressed, those days happened less and less, but nonetheless this bus driver would stop to check. Eventually, he began leaving things like a gallon of milk and some eggs, or note that would say, "I'm thinking of your family and wishing you well." At times, it was these gestures that buoyed my strength, as Manny's mom, to do whatever that day required.

When Joe and I decided to take action, our goal was to use our experiences to create a foundation that would remain flexible in addressing the unique needs of each family served. More recently, before the pandemic, our daughter Polly attended ECF's Crystal Gala and came home filled with joy in describing how ECF's mission remains relevant and strong as it continues to serve the real needs of families. One of the speakers, ECF kid Trevor, described many days when he and his family were exhausted and didn't want to see anyone, but that he always welcomed seeing his ECF case worker because she really knew him, his interests, his whole person... not just the disease. That's what ECF is – it is personal, about the whole family, adaptive to the needs of the moment, and fills in gaps where other services cannot. ECF is whatever you need because we are there listening at the moment you need it.

Joe and I could tell you how special Manny was to us. Those details are very personal and now, not the focus. Each child, each family that is helped in his name is unique but they share a universal human need – for the dedicated, intimate attention of a professional and volunteer community during what is one of the most difficult things anyone can ever face. Our hope is that, with this love and support, every ECF family goes on to embrace whatever comes next.

ECF needs you and your caring heart. Please consider helping our families, with great or small gestures, by making a financial contribution, designating ECF as your AmazonSmile charity of choice, volunteering, or whatever it is that you can offer. Thank you!

GIZA IS A MIRACLE AND YOU HELPED HER THRIVE





Her mom Rebecca noticed that Giza's left eye would drift sometimes. She never expected the doctors to say her daughter had cancer.

Giza was sent to Memorial Sloan Kettering for a biopsy. "There were 10 doctors in the room and it was scary," Rebecca

remembered. "I said a prayer while they put the mask over her face with the anesthesia. I recall seeing her eyes roll back as she was falling asleep, and it was such a punch to my stomach. Every time I think about it my eyes tear up." The doctors found eight cancerous tumors. "I did not believe it," Rebecca said. "I had to see those tumors with my own eyes. They wanted to inject poison into my baby's body. Was I to just take their word with no proof?"

When they showed Giza's mom the large tumors that she said "looked like planets," she couldn't stop crying. And so the treatments began, including chemotherapy, cryotherapy, and laser surgeries. Giza's mom struggled with feelings of numbness, isolation and fear. "I walked around like a zombie not knowing what was going to happen," she said. Then Rebecca was let go from her job and evicted from her apartment. Giza's dad left the family. Tears would come spilling out at odd moments.

Thanks to your generosity, Giza and her mom made it through this terrible time. She could pay their rent, put food on the table, and fill the car with gas to get to doctor's appointments. They received Christmas gifts, Easter baskets, and supplies for fun at home birthdays. "Giza never knew she would go without because she never had to," her mom said. "The outpouring of help made it so she would thrive through each chapter." Rebecca had to learn to thrive too. As the sole caregiver, she had to reinvent herself, becoming a realtor so she could work from home and take Giza with her on the job.

Over time, Giza got better. In fact, three of her eight tumors unexpectedly disappeared. "She is a documented miracle," said her mom. "Specialists from all over the world came to examine her, because they couldn't believe the tumors vanished." Though now in remission, Giza is visually impaired. She also suffers from chronic headaches, nightmares, and anxiety. A service dog helps her manage these issues, as does her joyful spirit, sense of humor, and love of singing. Her sunny personality is also helping her

adapt to the challenging world of Covid, enjoying virtual

playdates and birthday parties.

66 We are grateful for each day as it is a gift," says Rebecca. "We look to the future with hopeful expectation of wonderful things coming our way. 99



TIERELL AND HIS MOM ARE GRATEFUL TO YOU FOR BRIGHTENING THEIR EASTER.

EASTER was made so much brighter for so many ECF families, thanks to the generosity of donors and volunteers like you! See some of their smiles of gratitude!



EMMAELY IS ALL SMILES SHOWING OFF HER EASTER TREATS.



THE KUSCH KIDS LOVED THEIR EASTER BASKETS!

upcoming EVENTS

CORNHOLE TOURNAMENT May 16, 2021

10TH ANNUAL CHARITY BASH June 15, 2021

CENTRAL REGION GOLF OUTING July 19, 2021

SOUTHERN REGION GOLF OUTING August 23, 2021

VIRTUAL TRICKY TRAY June 19, 2021

BOCCE BALL-A-PALOOZA September, 2021

CRYSTAL GALA February 26, 2022

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