



## THE ENERGIZER BUNNY: Tony's Story

**For most kids, starting 7th grade is just a normal ending to summer.**

But for 12 year old Tony Salerno, it is a big deal. When he was only two and a half, Tony was diagnosed with stage 4, high risk neuroblastoma—just two weeks before his little sister Samantha was born. At Children's Hospital of Philadelphia, almost a two hour drive from their house in Holmdel, the Salernos were given very sobering odds of treatment success, despite the fact that the hospital is ranked number one in the world for treating Tony's type of cancer. At the time of his diagnosis, the survival rate for high-risk neuroblastoma was just 30% percent, a bleak outlook for a little boy just starting his life.



Tony began a grueling treatment path — five rounds of chemotherapy, surgeries to remove tumors in his abdominal cavity, two stem cell transplants, radiation and more.

*“But despite the exhausting treatments, Tony was always smiling and rarely complained. He was a favorite of his doctors and nurses for his positive spirit.”*

“He went to hell and back with a smile on his face the whole time,” said his mom Karen. “I can't tell you how many adults who have gone through chemo treatments have told me that when they had bad days they just thought of Tony, knowing that if he went through it, so could they.”

The Salernos learned about ECF from Karen's mother Betty, who has been involved with us for more than 30 years, holding numerous garage sales to raise money and providing donations to ECF families for urgent needs such as broken refrigerators or back rent payments. After Samantha was born, ECF brought diapers, baby food, toys and a high chair to her grandparents' house, where she was staying while Tony underwent treatment in Philadelphia. When Tony had resection surgery a week before his birthday, ECF delivered wrapped birthday gifts to Tony's house. During the holidays we provided presents for both Tony and Samantha because his mom “couldn't imagine getting out to the stores to shop.”

After Tony's stem cell transplant, when he wasn't allowed to be around other people because he was immunocompromised, ECF arranged a private tour for his family to go through the Six Flags safari, where he and Samantha got to feed giraffes, elephants and baboons from their hands. “ECF also invited me to attend a motorcycle rally where I was able to touch and sit on some of the motorcycles,” Tony said. “That was a big deal to a three year old boy!”

Though the treatments were ultimately successful, Tony endures many long term side effects, including lens replacements on both eyes due to cataracts, pins in his hips, and the loss of a kidney which causes him chronic hypertension and kidney disease. He takes ten different pills multiple times a day, as well as growth hormone injections and thyroid replacement therapy. His medical team includes a dizzying array of audiologists, ophthalmologists, endocrinologists, pulmonologists, orthopedists, oncologists, and more. But as throughout his ordeal, Tony does not let any of this get in his way. “He's like the Energizer bunny,” Karen said. “He just keeps on going...with a smile on his face no less!”

In many ways Tony is a very typical 12-year old — he enjoys having his summers off from school, swimming in the pool and playing video games. He loves being a boy scout and earning a variety of merit badges. He loves to play with his pet beagle, Cosmo. But Tony also loves to help others by volunteering his time with ECF and other pediatric cancer charities. His boy scout training only further inspires his desire to



help. “I have learned that the Boy Scout slogan is ‘do a good turn daily’ and I take that idea very seriously. I try to give back wherever I can.” Tony helps his grandmother with the garage sales and has unloaded groceries at an ECF food pantry. Even when Tony was nine and in a wheelchair from hip surgery, he volunteered with his family at a disaster relief center helping people affected by Hurricane Sandy. His little sister Samantha helps too; in honor of her brother she has donated her hair three different times to charities that create wigs for kids with cancer. “I think Tony is one of the bravest big brothers around,” Samantha said. **We think so, too.**

To learn more about ECF kids, upcoming events, or volunteer activities, visit our website at [www.emmanuelcancer.org](http://www.emmanuelcancer.org) and like us on Facebook at [facebook.com/EmmanuelCancerFoundation](https://www.facebook.com/EmmanuelCancerFoundation).



# reflections

FROM THE EXECUTIVE DIRECTOR



## IMPACT:

To have a strong effect on someone or something.

*synonyms: affect, influence, have an effect on, make an impression on.*

In this particular newsletter, I seem to have found a familiar thread that weaves in and out of the entire edition. There are so many sections — just about all of them — that talk about some kind of impact ECF has had...on the lives of families, staff members, volunteers and friends.

If you didn't notice, we spent a lot of time thinking of a new name and a new look for this newsletter. Something that represents the impact we want to express, and something that would have more of an impact on you, the reader.

When I took the position of Regional Director at ECF, over 24 years ago, I was immediately impacted by the stories of the families. The desperation of the diagnosis, the battle through the journey, the joy of remission, and the sorrow of loss. It is quite overwhelming. And that is from the perspective of an outsider, someone not faced with the diagnosis.

When I took on the position of Executive Director last year, I was even more immediately overcome with the weight of the responsibility. Families depend on ECF. They need ECF, and we have an obligation to do whatever it is within our abilities to help make life more manageable any way we can. Our staff and volunteers are among the most kind, caring, benevolent people I have ever had the pleasure of knowing.

I hope as you read this edition, you will think about what way you want to give back. *What is your story? What is the impact you want to make in this life?* We at ECF are so grateful for the impact you have already made through your generous support, which is what allows us to make the impact we do on so many families.

JOANN PASSANTINO

# to you

FROM THE DEVELOPMENT & COMMUNICATIONS OFFICE



“We make a living by what we get, but we make a life by what we give.”

Winston Churchill apparently said this, and it is why I go to work every day, here at ECF, where I have been the Development and Communications Manager since March.

When I was growing up in New York City, I longed for years to be a veterinarian, because I wanted to help animals. Unfortunately, my aptitude in science proved insufficient to pass even Bio 101 in college, so because I also loved to read, I decided to be an English major and emerged after four years wanting to make a career of writing. But I never lost that desire to help, to “make a life by what we give.” Writing grants and fundraising for non-profit organizations turned out to be that life. I'm not the one finding housing for the homeless, teaching job skills to prisoners, or digging wells to provide clean drinking water in a third world country. But nonprofits cannot do such essential hands-on work without the funds to pay the social workers, or purchase the supplies, or help pay the rent for a family about to be evicted because they have spent all their resources on uncovered medical treatments for their child who has cancer.

I have two children, ages 8 and 11, a boy and a girl, blessedly healthy. I am eternally grateful for that, and that gratitude fuels my desire to make a difference for the children helped by ECF, who for whatever errant twist of fate do not have the blessing of health. I, and all of us at ECF, are eternally grateful **for your support**, which is the very thing that allows us to make the day-to-day cancer journey of our cover boy Tony — who went from a 2-year old with no hair and tubes coming out of his arms to the confident and already accomplished 12-year old he is today — less arduous for him and his family. That is what ECF was created to do 33 years ago by a family whose lives were turned upside down by their own son's cancer battle and who wanted to give back to other families experiencing the same pain.

I will end with another quote, this time by Margaret Mead: *“Never doubt that a small group of thoughtful committed citizens can change the world. Indeed, it is the only thing that ever has.”* You — ECF supporters, volunteers, staff and board — are part of that group, and I am honored to be part of it too.

VICTORIA ARONOFF

We would like to thank all of our donors for “making a life by what [you] give,” including the following foundations, corporations, and organizations which provided recent grant support:

*Margaret and Peter Chang Foundation ♦ Independent Order of Odd Fellows of NJ ♦ JENNJOE Fund of the Community Foundation of NJ ♦ RevHealth Provident Bank Foundation ♦ Robert and Joan Dircks Foundation ♦ PNC Financial Services Group ♦ Monmouth Medical Center ♦ Builders' General Supply Company ♦ Party With Purpose ♦ Hyde and Watson Foundation ♦ The Westfield Service League ♦ The E.J. Grassmann Trust ♦ Westfield Rotary Club Foundation, Inc. ♦ St. Mark's Holy Name Society ♦ Meta C. Mergott Foundation ♦ Our Lady of Mt. Carmel Parish ♦ Abundant Life Reformed Church ♦ Benjamin Moore & Co. Innovation Data Processing ♦ Skanska Koch, Inc. ♦ Merrick Family Foundation*



let us REMEMBER

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Gabby



## EFC KID GRADUATES FROM COLLEGE— With Honors

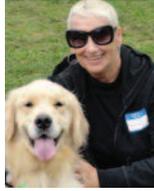
*“There were many times that I fell down, but I have been very lucky to have had friends to help me back up every time. The Emmanuel Cancer Foundation is one of those friends, and throughout my struggles and difficulties they have helped not only me, but my family as well.”*

Since Chris Nolze was diagnosed at age 12 with brain cancer and hydrocephalus, he has endured more than most people can bear. Over the 9 years of his cancer ordeal, Chris faced 21 surgeries, a brain hemorrhage, intractable hiccups, two bouts of painful trigeminal neuralgia, and other continuing health struggles. Despite this, Chris’s mother says he “doesn’t do anything small and takes advantage of every day.” Recently, Chris graduated from Ocean County College with an Associate’s degree in Science with Honors, Alpha Beta Gamma, Phi Theta Kappa Honors Society. He also received the Ocean County College Board of Trustees award, and this fall started continuing his studies at Kean College.

Throughout his battle with cancer Chris has been a role model to his Toms River family and everyone around him. His mom says these are the principles on which he bases his life: **Never give up. Always believe in yourself. Fight for what you believe in. Stay strong. And don’t lose hope no matter what life brings you.** ECF is so proud of Chris!

## voices FROM THE REGIONAL CENTERS

### CENTRAL REGION



Since my nine-year anniversary in May, I have been reflecting on my time spent working at ECF. When I took this job, my main goal was to give back to others, and this position has given me the opportunity to do just that. Little did I realize that I would be getting so much more in return. The children are amazing. Their spirit inspires me every day. I smile when I think of them and when I see their faces light up with happiness when they receive holiday gifts or birthday bags from ECF. At holiday parties, you can actually see the twinkle in their eyes as they meet Santa Claus or make a holiday craft for their mom or dad. One family recently was so very happy to receive assistance from us in paying their mortgage and purchasing badly needed mattress covers and pads — it made my day but, most importantly, theirs too. They have taught me to live one day at a time and have brightened my life in ways I never would have expected. They are in my heart and will be there forever, and I am truly thankful for that. — *Barbara Kopel*

### EASTERN REGION



I began my journey at ECF thinking how wonderful it would be to help these amazing children and their families. Little did I know how much they would inspire me and how grateful I would be to know them. One memory I will carry with me forever is meeting the Manheimer family, whose story touched me deeply. I was working for ECF just under a month when I received a phone call from their mom Toni. One of her three daughters, Megan, was diagnosed with a brain tumor and she needed our help. Monthly food deliveries began, holiday meals and gifts were provided, and birthday bags were given to each child. At the holiday party, each of them hugged and thanked me. The three sisters gave me drawings they colored, which I still have hanging in my office to remind me of that day. Each and every one of ECF’s families has a special story and their strength and courage is inspirational. I feel so very blessed and grateful to be a part of this amazing ECF team. — *Rose Contreras*

### NORTHERN REGION



I am coming up on my one year anniversary as the Northern Regional Director. I could not have anticipated the profound effect ECF has had on me and our ECF families. I have witnessed many moving moments, from volunteers giving their time to deliver groceries and assist with food drives, to holding pasta dinner fundraisers and making holiday gift baskets. Kids get involved too — the 14 year old daughter of an ECF board member launched a business with her friend selling cookies and cupcakes with 100% of profits going to ECF (they’ve so far raised \$1,000!) A 15 year old girl recently designed her own beautiful note cards with the proceeds going to ECF. It is thanks to all these acts of kindness and generosity — and to our dedicated supporters — that we are able to truly help our families in so many ways. I look forward to another year of making a tremendous impact on ECF families in the Northern region. — *Patricia Brussel*

### SOUTHERN REGION



While I have been busy welcoming new families and continuing to help those who have been with us for many years, I am profoundly touched by families such as Jason’s, who live in Woodlynne, NJ. When Jason was diagnosed with Leukemia five years ago, his family was devastated emotionally and financially. ECF has been helping them get through their ordeal — their caseworker used the ECF emergency fund to help pay their utility bills and other necessary expenses. This past December, their microwave broke and with a family of five children, they used this handy appliance quite often! Thanks to the generosity of the Independent Order of Oddfellows, we were able to provide the family with a brand new microwave. Then, after a recent visit by their caseworker, it was determined that four of the children were in desperate need of new mattresses. With the help of generous donors and the kindness of a wholesale mattress company in Cherry Hill, we were able to supply all of the children with new, safe, clean mattresses! I’ve enjoyed getting to know families like Jason’s and helping with anything they need, whether big or small, and I am looking forward to the holiday season and getting everyone’s wishes fulfilled! — *Melanie Giblin*



## CREATE YOUR CHARITABLE LEGACY

A simple, flexible and versatile way to ensure ECF can continue our work for years to come is a gift in your will or living trust, known as a **CHARITABLE BEQUEST**. Please consider including a bequest to ECF in your estate plan.

**For more information, call (908) 322-4323 ext. 15.**



### Landon's Story

19 month old Landon is described by parents as "super funny, adorable, crazy and talkative... just a regular kid."

But recently Landon's left eye started to bother him and his parents noticed color changes in his pupil. They thought it might be lazy eye since Landon's dad experienced that when he was a child. Unfortunately, in July, Landon was diagnosed with Retinoblastoma, a rare cancer of the retina that affects an estimated 200 to 300

young children annually in the United States.

Shortly after his diagnosis, Landon had his first round of chemotherapy and is slated to undergo three additional chemo treatments. If the treatment does not shrink the tumor behind his left eye, Landon will need surgery to remove it. So far the chemo has caused a slight change in the size of the tumor, but the doctors say it is still too early to tell what the next steps may be. Landon's family was told that there is a 60% chance that the eye will need to be surgically removed.

Landon's dad Tyler says the impact of this diagnosis has been significant. He and Landon's mom Brittany have lost time at work having to take off so many days to bring Landon to the doctor, resulting in loss of income and difficulty in paying their bills. The couple spends less time with each other and with Landon's sister Aubrie because of their focus on Landon's treatment.

*"ECF has helped the family with grocery donations and financial assistance in paying monthly bills, and visits from their caseworker Ilene offer the parents an outlet to express their rollercoaster of emotions."*

Despite his diagnosis, Landon keeps on doing the things he loves—going to the park and playing with trucks and cars. Only during the first week after his chemo did he slow down at all, sleeping a lot and not eating much. And even though his loss of vision sometimes causes him to bump into things or walk into walls, he still just loves running around like a "regular kid." ECF hopes and prays that Landon's treatment is successful.



### upcoming EVENTS

For more information call us or visit our website!

- HOLIDAY BOUTIQUE December 1 • Ridgewood, NJ
- ECF SOUTHERN HOLIDAY PARTY December 3 • Mullica Hill, NJ
- ECF CENTRAL HOLIDAY PARTY December 11 • New Brunswick, NJ
- CRYSTAL GALA March 18 • Asbury Park, NJ
- BASH AT THE BRICK HOUSE March 31 • Wycoff, NJ
- SPRING TEA April 30 • Brick, NJ

## volunteer SPOTLIGHT: Teenagers Paige and Emily

The stereotype of a high school student is someone who is only interested in their friends and their cell phones.

ECF volunteers **Paige Crandall** and **Emily Boyle** defy that image, having spent many hours of their time as students at Scotch Plains-Fanwood High School dedicated to making a difference for kids with cancer. Over the past four years they have helped ECF in many ways including packing food in the pantry, doing data entry, online research, and stuffing envelopes, as well as making crafts with kids at the annual holiday party, walking down the "runway" in a fashion

*"I have loved volunteering at ECF, and I have felt so comfortable and welcomed every time."*

—EMILY



show, and assisting with the Tricky Tray event. Paige's dad helps out too; he is a photographer for the *Westfield Leader* and *Scotch Plains-Fanwood Times* and takes photos for us at ECF events. ECF will miss Emily and Paige while they are at



*"My relationship with ECF has been a rewarding aspect of my high school career and volunteer service."*

—PAIGE

Lafayette College and Delaware College, respectively. Their hard work has meant a lot to ECF, and has made an impact on Emily's and Paige's lives as well. They will be missed by ECF Senior Regional Director Barbara Kopel, who worked closely with these teenagers and fostered their excellent volunteer efforts.

### CONTACT US

To receive our services, refer a family in need, volunteer at any of our four regional offices, or to make a donation:



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