

# ECFvoice

THE NEWSLETTER OF THE EMMANUEL CANCER FOUNDATION



## ECF KIDS DOING GREAT: DIEGO



**Diego is a typical 8 year old boy who loves Legos, Batman, and playing with his friends.** But unlike many other boys his age, he is excited to be in school every day, because last year he wasn't able to go at all due to his treatment for acute lymphocytic leukemia, which was diagnosed in 2015. Diego endured a year of both inpatient and outpatient chemotherapy, and was often sad

about his long, isolated stays at home and not being able to be the active boy he was before he got sick.

When ECF Caseworker Caitlin first started visiting the Saddlebrook family, Diego was pale and had lost his hair. He barely looked at Caitlin, who provided emotional support to Diego's frightened parents and helped them understand their son's own emotional ups and downs.

*“Every time Caitlin visited the family she would bring Diego a toy—mostly Legos of course—and over time he warmed up to her, giving her a shy smile whenever she came through the door.”*

ECF also helped the family financially with monthly grocery deliveries and gift cards. Diego's mom had to stop working after her son's diagnosis, and his dad's construction work slowed during the winter months when Diego first started his treatment, causing medical and other bills to pile up.

Fortunately, Diego is now down to only monthly maintenance chemo and spinal taps. Though he doesn't feel well for a few days after these appointments, his overall renewed energy has allowed him to return to school full time, start taking guitar lessons, and play with his many friends as often as possible. In January, Diego was finally able to have the kind of birthday party he wanted last year but was too weak to

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## AND NICHOLAS!

**The challenges of cancer don't end when the child is in remission.** Though 8-year-old Nicholas has been free from cancer for two years and is doing fine, every time he goes to the doctor for his monthly check up, his mom Patricia's emotions go on a roller coaster ride of apprehension to relief and back again. Added to that stress, one of Nicholas's older brothers has a heart condition and his other brother recently had surgery to repair a sports-related knee injury. With this and the continued financial repercussions from her son's battle with cancer, Patricia still relies on regular ECF caseworker visits for emotional support and on monthly grocery deliveries for adequate food.

Nicholas was diagnosed with Burkitt's lymphoma when he was five, after months of doctors insisting his persistent stomach pain was constipation. During his treatment that required long hospital stays and a year off from school, Patricia had to quit her part-time job. His dad lost his job soon after Nicholas' diagnosis and then took a significant pay cut for the new position he attained. Putting all their time and money into Nicholas's treatment, the family's financial situation became unmanageable, so ECF helped by covering oil deliveries for their heat, providing gift cards for gas and groceries, and using Facebook to find donations of a refrigerator, washer and dryer when the Stockholm-based family's machines broke down.

Scared and clingy to his mom during his cancer ordeal, Nicholas is now an active and upbeat boy who loves playing with his older brothers and his friends. His mom's experience has inspired her to help other families



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## upcoming EVENTS

ECF holds many enjoyable events throughout the year. Please visit our website for more information:  
[www.emmanuelcancer.org](http://www.emmanuelcancer.org)

**BASH AT THE BRICK HOUSE**  
March 31, Wycoff, NJ

**TRICKY TRAY**  
April 22, Scotch Plains, NJ

**SPRING TEA**  
April 30, Brick, NJ

**ECF GOLF OUTING**  
July 17, Deal, NJ

# reflections

FROM THE EXECUTIVE DIRECTOR



**SOMEONE ONCE SAID:**  
*"Coming together is a beginning; keeping together is progress; working together is success."*

**F**ull-circle. Before embarking on my new journey with ECF one year and 8 months ago, I spent the better part of 21 years as the Eastern Regional Director. I was involved in the ins and outs, ups and downs of the family service portion of ECF. I was always on the search for another food drive, another Wish List Donor, someone to adopt birthdays or folks to fulfill the many concrete needs our families have.

After becoming Executive Director, I threw myself into finding ways to expand our donor base, raise money for our Emergency Financial Assistance Fund, uncover new ways to reach more families...the administrative responsibilities are endless.

But a few weeks ago, I did a speaking engagement at Dialight, a local company, with the new Eastern Regional Director. During this speaking engagement, one of the employees turned out to be mom Leslie, featured on the next page of this newsletter. Her daughter, Tiffany, is a girl that I had come to know and love. Her passing was one of the saddest days of my life. Seeing Leslie again, and hugging her, brought back all the memories of all the children that I had worked with over the years. It reminded me of what is really important. Coming together, working together and keeping together. Coming full-circle. That is what Leslie and I did.

JOANN PASSANTINO

## meet a board member: JOEL MARKEL



*"To save a life is to save the world,"*

says Joel Markel, past president of ECF and lifetime member of its board of directors. Joel lives by this credo, transforming a terrible tragedy in his family into service to others.

In 1990, Joel's five-month-old son Ryan was diagnosed with a malignant liver tumor. He and his wife Stephanie spent months travelling to and from New Jersey to Children's Hospital of Philadelphia for Ryan's treatment, all the while caring for their other child, four-year-old Jimmy, who despite his young age was, according to Joel, deeply affected by his brother's illness. The hospital suggested they contact ECF to help them get through this unimaginably difficult time.

In addition to helping pay tolls incurred during the long daily rides to Philly, covering phone bills and getting kosher meals delivered to Stephanie during her stays with Ryan at the hospital, an ECF caseworker provided much needed emotional support. "ECF was there for my whole family," said Joel. "They offered emotional care for all of us—parents and siblings." After Ryan sadly passed away at 11 months old, Joel and Stephanie promised themselves they would pay ECF back for assisting them during their ordeal. He first went on the organization's service committee, was nominated to the board, and then served as president from 2011 to 2016. He has generously offered his expertise, resources and compassion to ECF for over 25 years.

In the wake of the family's grief, Joel also turned his attention to the idea of helping others who were experiencing the same pain his family went through. "Shortly after losing my son, I tried to start a support group for fathers who had lost children. But I saw there was little interest among men to share their feelings." Looking around for other ways to channel his desire to help others, an opportunity came up to purchase a small home health care agency. Joel jumped on the chance, as he had found it difficult to find qualified and committed caregivers who could tend to his family's needs. Joel turned this small agency into Preferred Home Health Care and Nursing Services, a leading provider of medical and non-medical home health care in New Jersey and Pennsylvania.

But Joel doesn't stop at running a successful business and supporting nonprofits. He is also the host of a syndicated radio program, "Preferred Company," heard on a number of stations in New Jersey and New York, as well as the executive producer of a recent film *Oro Macht Frei*, a documentary about the Italian Jewish experience during the Holocaust that has been screened in Italy and numerous film festivals across North America. Joel and his wife live in Morganville, though he is originally from Brooklyn.

*"I serve on other nonprofit boards, but ECF has a special place in my heart."*



### 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.**

## ECF MOM GIVES BACK IN MEMORY OF HER DAUGHTER



When Tiffany Jean Berger was a teenager and terminally ill with cancer, she wasn't afraid for herself, but afraid for her mom, worried about leaving her mother all alone without her. That was the kind of person Tiffany was — bubbly, helpful, loving, always with a smile on her face, despite her grueling nine-year battle with cancer. "She was my best friend," said her mother, Leslie, who says she has never stopped missing her daughter since she passed away in August 2003 at

the age of 21. "To get through it you have to live day to day and help whoever you can," said Leslie, who has been doing just that by giving back to ECF — which helped her and Tiffany during their ordeal — through her company, Dialight, a commercial lighting firm where she has worked as a credit analyst for almost thirty years.

*“ECF was so important to me and Tiffany. Thanks to them, Tiffany had wonderful birthdays and holidays.”*

ECF also donated a car to Tiffany when she turned 17 and provided other financial as well as emotional support. "When your kid is sick you are oblivious to the world around you and think you don't need any help," said Leslie, who as a single mom working full time quickly realized that she did need help. By the time 12-year-old Tiffany's Stage 4 Hodgkin's Lymphoma was diagnosed in 1994, the cancer had already spread to her chest, underarms and groin area.

What followed was a series of highs and lows, months of chemotherapy and radiation, grateful remissions followed by devastating relapses. She had two exhausting bone marrow transplants, each requiring six weeks of isolation only seeing her mom and a litany of nurses and doctors. Leslie remembers that one Christmas after a transplant, Tiffany's only contact with the outside world was a little window on the door where she could see Santa making visits to other children in the hospital. Leslie felt that Tiffany was never the same after the transplants, using a wheelchair much of the time, needing help with daily tasks, and suffering painful recurring episodes of shingles and pancreatitis.

But Tiffany remained cheerful and focused on trying to have as normal a teenage life as she could. She attended four years of high school, though only for a few hours a day. She loved the computer she got from Make A Wish Foundation and playing with her three cats Kalee Cat, Dexter and Little Charlie. Even though Tiffany was often weak and had limited mobility, she and her mom liked to go to Great Adventure and sit on a bench and people-watch. And Tiffany had signed up to attend Brookdale College to study computers, which had become her passion. Unfortunately, soon after her high

school graduation, Tiffany's cancer returned and she went on another grueling treatment regimen that kept her from starting college.

In 2003, Tiffany was back in the hospital. A large tumor in her stomach had ruptured. Her mom sat with her for four days until she died on August 26. "I felt she was comforted at the end when I told her that grandma and her uncle would be waiting for her in heaven, but that her two cats would push them out of the way to see her first."

For a long time, Leslie lost touch with ECF. Then last fall she was cleaning out a box and found an old ECF newsletter that featured a story on Tiffany. The next day Leslie brought that newsletter to work and showed it to her



coworkers with the idea of getting the company involved in helping other families that were going through the same pain and difficulty she had experienced. Inspired by Leslie's story, Dialight decided to "adopt" an ECF family whose teenage daughter Mckenzy was battling cancer. Leslie and her company donated everything on Mckenzy's and her three siblings' wish list, as well as gift cards for the parents. The dad fought back tears when he saw the overflowing trunk full of gifts being delivered to his family.

ECF decided to honor Leslie and Dialight as *Business of the Year* at our Crystal Gala on March 18 and conspired with Leslie's colleagues to surprise her one day recently with this award prior to the event. ECF Executive Director Joann Passantino remembers how Leslie walked into the Dialight conference room expecting a regular staff meeting and how she was confused to see the ECF logo projected on the wall. "When I walked towards her, Leslie's whole face changed and she fell into my arms crying and hugging me," said Joann. "She just kept saying she couldn't believe it. Everyone in the room cried." Leslie went on to tell her coworkers how much ECF meant to her and Tiffany and about all the many things they provided that most people don't consider as vital needs for families facing cancer—money for gas, food for the parents to eat while in the hospital, and supplies for kids using feeding tubes. Leslie keeps the award on her desk, and it reminds her of how generously Dialight stood behind her over the years when she was caring for Tiffany.

Leslie now lives in Toms River with eight cats, who she credits with inspiring her to keep going. "Tiffany loved cats and would want me to take the best care of them," she says. Leslie continues honoring Tiffany's memory not only by providing joy to other ECF families, but through activities on behalf of other organizations focused on children. Leslie recently took part in the "Seaside Heights Polar Plunge" benefitting the Special Olympics. She was the only woman on her 10-person team, whose brief dip in what Leslie calls "bearable" water raised over \$3,000 for the charity. "I think this was the first time since losing Tiffany that I really enjoyed myself," said Leslie. "I know in my heart she wanted me to have fun."

## to you

### FROM THE DEVELOPMENT & COMMUNICATIONS OFFICE

As I enter my second year at ECF, I continue to be astounded at two things: 1) The incredible strength and resilience of children facing cancer and 2) the amazing generosity of so many donors like yourselves wanting to make these kids' lives better.

The stories in this newsletter are not only meant to introduce you to ECF families, volunteers and fellow donors, but also to give you a sense of how much your support means to these families—and to ECF! We are grateful to all of you, including the following foundations and corporations that provided recent grant support:

Ameriprise Financial • The Arnold A. Schwartz Foundation • Automotive Masterminds • Benjamin Moore & Co. • Bristol-Myers Squibb • Builders' General Supply Company • Church & Dwight Employee Giving Fund • Coastal Community Foundation • Ellis Family Charitable Foundation • Gannett Foundation GMJ Investments, LLC • Hair Foundation • Investors Foundation • JENNJOE Fund of the Community Foundation of NJ • Jersey Shore Cross Fit • Johnson & Johnson Family Companies • Julie Dance, Inc. • New Jersey Multiple Listing Service, Inc. • Preferred Home Health Care & Nursing Services Rite Aid • Select Equity Group Foundation • St. Elizabeth's Church • Shapiro Family Foundation • Staples • The Hinman Foundation Thomas and Mary Ann Tizzio Foundation • Thomas H. Hamilton Foundation • The Westfield Foundation



*Victoria*

VICTORIA ARONOFF

# volunteer SPOTLIGHT:

## Mikala Allen

Mikala Allen remembers ECF volunteers and caseworkers coming to visit her family over two decades ago when her younger brother Norwood, known as "Woody," was diagnosed with Leukemia.

"I was always so happy to see them," she said. They brought food and gifts, offered emotional support to Mikala and her three other brothers, and helped her deal with the pressures of being Woody's bone marrow donor, when none of her other siblings turned out to be a match.



“They made me feel like a superhero for being a donor.”

She also remembers how the ECF caseworker explained the medical terms related to her marrow donation and her brother's illness, helping her understand what both she and her brother were going through. "I turned 14 the May before Woody passed, when he was 12," Mikala said. "The experience was indescribable for me as a child and still as an adult. I just wanted my brother to get better."

Two years ago, when Mikala heard about an opportunity to volunteer at an ECF Family Holiday Party, she jumped at the chance to get involved. She has been volunteering ever since, primarily doing regular delivery of birthday baskets to local ECF families. She said families are always grateful for what she brings, but sometimes are most appreciative for having someone to talk to about the difficult time they are going through.

Her three children, ages 18, 13 and 12, sometimes come with her on deliveries, and now her parents want to get involved volunteering too. Mikala, who lives in Winslow Township, is a sociology professor at Camden County College and the Basic Literacy Coordinator for Camden County. Her husband is also a professor, at Rutgers University. We at ECF want to thank Mikala for her dedication to helping other families get through the painful ordeal of pediatric cancer.

## 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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## voices FROM THE REGIONAL CENTERS

### CENTRAL REGION



Jennifer, a 12 year old ECF kid from Plainfield, walked into our office with her dad to pick up the holiday gifts donated to her and her younger brother Wilfredo. Her expression said "WOW, these gifts are all for me and my brother?" She was so very happy and excited; it brought tears to my eyes. This was a very precious moment that made my heart happy and that I will always remember.

—Barbara Kopel

### EASTERN REGION



One of our families in Trenton is struggling with the financial strain related to caring for their 6-year-old son Brima who eats through a feeding tube for which supplies are expensive. In addition to assisting them in purchasing the supplies, ECF is contributing to other expenses as well. Brima's mom Gaya told Erin, her caseworker, "Thank you very much for the Visa gift card to help us buy gas. I literally cried today when we received it! The world really needs more people like you. Thank you so much!" Being able to provide what these families need is so rewarding and notes like this are very special to me.

—Rose Contreras

### NORTHERN REGION



A Weehawken family we help is struggling financially during this difficult time since their son's cancer diagnosis. The single mom was laid off from her job and she has been unable to look for a new one due to the time she spends taking care of her son. We try to make their journey a little easier with regular grocery deliveries, gift cards and the emotional support of her caseworker. The mom is constantly thanking us for our kindness and how she appreciates everything we do for her son.

—Patricia Brussel

### SOUTHERN REGION



I am very excited to be the new Southern Regional Director, a role I held at ECF back in the 1990s when I originated the Southern Outreach Center. Though I just started a few weeks ago, I am already busy recruiting new volunteers, getting out in the community and spreading the word about our services, and working hard to provide the region's families with everything they need—and looking for affordable office space for ECF! One family who lives in Burlington County struggles financially---12-year-old Caron has brain cancer and is currently bed-ridden. He and his siblings live with their mom and grandmother. When I called about giving the family supermarket gift certificates, the grandmother was overjoyed. She said they had just prayed about their need for food, since their supplies were very low. I am so happy to once again be part of this great team and make a difference for these families. —Mary Ann Sullivan

### DIEGO CONTINUED FROM PAGE 1

have—jumping up and down in bouncy houses! Caitlin still visits the family every month and continues to bring Diego a Lego each time!

Diego is also making his first communion in May at Mt. Carmel Church in Ridgewood. The church is a generous donor to ECF and recently ran a fundraiser for Diego and several other ECF families. Mt. Carmel happily stepped in to help Diego when his local church's communion preparation class could not accommodate Diego's treatment schedule; sometimes he doesn't feel well enough to attend class every week but goes as often as he can and is getting well prepared for his special day. *We are so happy Diego is doing well and getting to be a typical 8-year-old kid!*

### NICHOLAS CONTINUED FROM PAGE 1

facing pediatric cancer—she set up a fund to raise money for families in her area and spoke at ECF's Bash at the Brickhouse fundraising event, hoping her story of how ECF assisted her family would touch the hearts of potential ECF supporters. *ECF is grateful for her efforts and Nicolas's good health!*