

# Outlook

The Newsletter of the Emmanuel Cancer Foundation



Autumn

Created in collaboration with the Independent Order of Odd Fellows of New Jersey- proud partners in support of kids with cancer. [www.ioofnj.org](http://www.ioofnj.org) 2009

## ECF Kids - Where Are They Now?

*David Carey talks to ECF about his journey...*

### How long ago did your family receive services from ECF?

The help from ECF started just after I was diagnosed, when a really great counselor named Ellen came to see my family. Ellen helped us for several years.

### How old were you at the time, and what was your diagnosis?

I was diagnosed with leukemia the month before my seventh birthday, on May 7, 1997. My mom will never forget that day.

### Can you give some examples of what ECF did to help your family?

I especially remember how much fun it was to receive the birthday boxes, filled with cake mix, icing, candles, hats and party supplies. I know my family really appreciated the special holiday grocery deliveries, too. They were a tremendous help. But most of all our Caseworkers were always there to help us through the entire ordeal.

### Can you tell us a little bit about your personal experience with cancer?

I remember how upset my mom used to get when my counts were low. And I can remember how hard it was for both of us when Ryan (another ECF kid) didn't make it through. We were both scared and sad. At the same time I was in treatment for my leukemia, my parents were getting divorced. That made things

so much harder for everyone, including my older brother and sister. My mom's meetings with our Caseworker really helped her a lot. So did the relationships she made with the other parents whose kids were undergoing chemotherapy. We never really felt alone during this time. The ECF parties were helpful in getting to see other kids, and their siblings still doing normal stuff. It made things easier. I remember that as each family moved on when their kids were done with treatment, it made things more hopeful for those of us waiting our turns at being 'done'. I was glad when it was my turn to see the end of the tunnel.

### How old are you now, and what have you been doing with your life since that time?

I am 19, and I am a sophomore in college.

### How did your mom become a volunteer for ECF?

She felt with all the help she was given when we needed it the most, that she needed to put it back so the next one who needs it can get it as well.

### In what capacity does she volunteer?

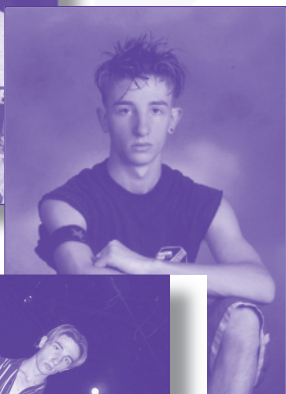
She helps out by bringing food to the pantry, and by talking to other families when they want to talk to someone who has been there.

### Who are your role models and why?

I would say my mom and my family and friends who stood there by my side through all of this and made the time pass.

### Where do you see yourself in ten years?

I hope to be a rock and roll icon. I am now in a band called 'Just Enough.' When I was ten, I went on "Kids on Air", on the 94.3 The Point FM. This Sunday morning show with Lou Russo featured ECF kids as co-hosts. I told them I wanted to be in a band and Lou told me, on the air, that if I ever made a CD, to come back and talk to him. Little did he know that I was going to hold him to his word. I went back when I turned 18, after my mom dropped off a copy of my CD at the station earlier. Lou called me in, and interviewed me on the air, and then played one of our original songs.



## Reflections from the Managing Director:

Dear Friends,

No matter where you are or what you are doing it is difficult not to find yourself involved in the healthcare debate happening across our nation. Wherever you stand on this issue, I am sure you will agree that the debate has successfully inspired us all to think about what is happening now and about the future of healthcare in America.

I recently found myself reflecting upon how all this impacts ECF's children and their families who find themselves in the middle of the conversation with so much at stake - most importantly, the life a child who may be newly diagnosed or one who has been battling cancer for years.

There are some aspects of health care that the system will never address, like family counseling, food, clothing, and keeping the heat on in the home of a cancer-stricken child in the winter. Doctor visits, treatments, and even a lifetime of medications are vital components on the road to recovery for every child with cancer. But the support services ECF provides that also help the family survive will be overlooked because they are often considered ancillary.

At ECF, these services have been at the core of our mission since our inception 26 years ago. And they are still the heart of what we do today.

As you read this edition of Outlook, you will learn more about some of the families we support, and some of the situations they face in the course of their journey towards health. All of these stories are real, and families like Maia's, Carla's and Mark's have encountered incredibly challenging circumstances, *in addition to battling cancer*. Without Caseworkers like Eileen, Jim, Evelyn, Kim and Amy, without the coordination with and the quick response of the Regional Directors, these families would not receive all we can give them.

Most of all, without friends like you, who care about these kids, we would be unable to continue to reach out to these and to all of the new families – our numbers are higher than they've ever been before – and make sure we are doing all we can to help them through this.

Warm regards,



Carol Davis, MA, LPC  
Managing Director

# ABOVE and Beyond

Ten-year old Zachary and his older brother, Richie, live in Salem County. Zach has the most common type of cancer in kids, acute lymphoblastic leukemia, diagnosed almost four years ago. When the brothers attended the Southern Region's Chocolate Event in February, along with their Caseworker, Kim Cranstoun, they both tried so hard to win a signed baseball from Geoff Jenkins who plays for the Philadelphia Phillies. Kim even put all of her own chances into the Tricky Tray, in an attempt to win it for them. The boys were heartbroken when they didn't win, but they still had a wonderful afternoon indulging in chocolate treats and enjoying the entertainment.

But Kim didn't forget about their disappointment. When Zach's mom invited her to "Zach's New Beginning," his end-of-treatment party in May, Kim, who is friends with one of the weather/traffic newscasters for 6ABC in Philadelphia, contacted her friend for help. The friend came through by reaching out to a retired major league baseball player named Curt Schilling who used to play for the Philadelphia Phillies. Curt sent not one, but two personally autographed baseballs to Zach and Richie. Because Curt Schilling may actually make it into the Baseball Hall of Fame, the baseballs may just turn out to be real collectibles. The Phillies sent an assortment of t-shirts, hats, and baseball cards, and Kim's contact also got personal autographs from most of the news people from the morning edition for the boys. Thank you Kim, for making their day!

Working with another family, Kim went to see Daria for the first time recently. With two other children in the household, and at times an exasperated mom, Kim spent three hours on this first visit. She left there knowing that she had much more to do for this family, when, the very next day, Mom called her to discuss her financial difficulties. She was in desperate need of rental assistance, and the hospital social worker, who might have other resources, was on vacation. With rent due the next day, Daria's mom was terrified, and Kim feared that because it was late on a Friday afternoon, she would not be able to locate another organization besides ECF to help. So, Kim turned to the one place she knew could help---TD Bank. She sent out a pleading letter to her husband, who is undergoing his own battle with cancer. He rallied his entire department in the main office of TD Bank in Mount Laurel, and within one day they raised \$400 to help Daria's family. When Kim dropped off the check the next day, she was greeted by mom with a hug, some tears and much appreciation. ECF is so grateful to TD Bank and its employees, and to Kim and her husband for their loyalty and quick-thinking.

ECF's Caseworkers help in other ways, too, often going "Above & Beyond" in order to benefit the families. Eileen Appelbaum recently celebrated a family member's 75th birthday by making a donation to ECF in his honor, and Evelyn Dormekpor, who works so hard with her families, sent us a contribution "just because". Jim DeMontigny finds creative ways to advocate for his families, always getting the most out of relationships ECF has with other organizations. He demonstrates time and time again that he is determined to complete the process from beginning to end to assist the families out of any crisis. We thank each and every one of you for your dedication.

*Please help kids with cancer by using iGive for shopping on the Internet. Before you go directly to a website to make a purchase, visit: [www.iGive.com](http://www.iGive.com) and be sure to designate the Emmanuel Cancer Foundation as your charity. You can also use this as your search engine to benefit ECF families. It's easy and free.*



It's simple to send your well wishes to ECF kids.

Visit: [www.compassionatecommunications.com](http://www.compassionatecommunications.com)

and be sure to click on the link that brings you the faces of the ECF kids who are waiting to hear from you!

## Charitable Foundation

TD Bank through the TD Charitable Foundation has provided a first-time grant of \$7,500 to support ECF's programs. We are extremely grateful for this support and we look forward to a continued partnership!

## Independent Order of Odd Fellows Renews Support for ECF

A gift of \$31,000 was presented to ECF by the Odd Fellows Grand Lodge of New Jersey on June 25th, at their annual ceremony at the Resorts Casino Hotel in Atlantic City. ECF's Board Secretary, Steven Wooton, who is a member of the IOOF, was instrumental in the creation and continuation of this partnership between the organizations, now in its fourth year. It is important to note that various lodges of IOOF have been supporting ECF since 1997. Also representing ECF was Central Regional Director Barbara Kopel.

## Real Families – Real Crises

**Carla is in a coma.** Now 16 years old, she was diagnosed with ALL, a type of leukemia, at the age of 12. She was treated with chemotherapy and a transplant, and then went into remission. She did well until this February when a routine follow-up visit revealed that she had relapsed. She was again treated with chemotherapy, but this time it had no effect. So, Carla was sent to NIH for experimental treatment. While in Bethesda, they discovered she was misdiagnosed and that she actually had a different form of leukemia. She was sent back to the original hospital for more treatment and another transplant. The transplant caused her brain and lungs to bleed. She was in severe pain and she was moved to intensive care where a coma was induced. She is now receiving treatments which have stopped the bleeding in the lungs and slowed down the bleeding in the brain. However she is still in extremely critical condition.

While mom is by Carla's side, dad's employer shut down operations and he is out of work. As a result mom and dad were unable to keep up with the mortgage payments and the family is foreclosing on their home. Three of Carla's siblings are staying with their maternal grandparents. When Carla comes home, her parents don't know where they will all live.

James DeMontigny, the family's Caseworker, and Laurie Ehrlich, ECF's Southern Regional Director, collaborated to provide the parents and grandparents with support and guidance as well as with grocery deliveries and gift cards. ECF has also granted financial aid to the family, and arranged for them to receive bedroom furniture when they moved into their home two years ago. James has reached out to other organizations for additional help.

*Note: We are all so sad to report that Carla lost her battle with cancer on September 16, as a result of a bacterial infection from her bone marrow transplant. As per her wishes, her family will have a "good-bye party" to honor Carla's memory. ECF will continue to work closely with Carla's family, especially her mom.*

**Maia quit school and found a job as a waitress at her local diner in order to help support her family.** At 19 years old, she had hoped to use this time to mold her future and to train for a career. Despite the fact that Maia has been in remission for two years, this comes only after she had a relapse of her cancer prior to the five-year mark, so she is now considered high risk and is closely monitored. This terrifies Maia, who is reluctant at times to go for the follow-up appointments, for fear of

the results. When she had swollen lymph nodes last year, and it turned out to be a virus, she breathed a huge sigh of relief. But the challenges that she and her family face are still enormous.

After being in two separate accidents, her father is frequently in and out of the hospital, and her mother is now out of work due to her own illness. The family has no health care coverage, so mom is unable to get the care she needs nor can she pay for the medications she needs. As a result of the financial situation, the family was evicted from their apartment and they were forced to move in with relatives. Mother and father had to split up. Mom and Maia are living with Maia's older sister and her family in a small, two-bedroom space. Maia's father is living in his own apartment in Camden.

The other day, Maia went to visit her father and she found him lying on the floor tied up and bleeding. He had been the victim of a home invasion. He had been beaten and kicked by three men. He was forced to give them \$500 or they threatened to kill him. He was treated at the hospital and released. The Camden police told him a man nearby was held up at gun point by three men, beaten and left on the sidewalk. Maia's father is lucky to be alive.

Through the coordination of the advocacy of two of ECF's Caseworkers, James DeMontigny and Evelyn Dormekpor, they found an organization that is willing to help if the family can find someone willing to rent to them. We recently learned that there is a willing landlord, but the family does not have enough money to put down. So, ECF is providing financial assistance to the family, and with the aid of the other organization, they will be able to move in. The remainder is coming from Maia and her sister, who are both working overtime to make this happen.

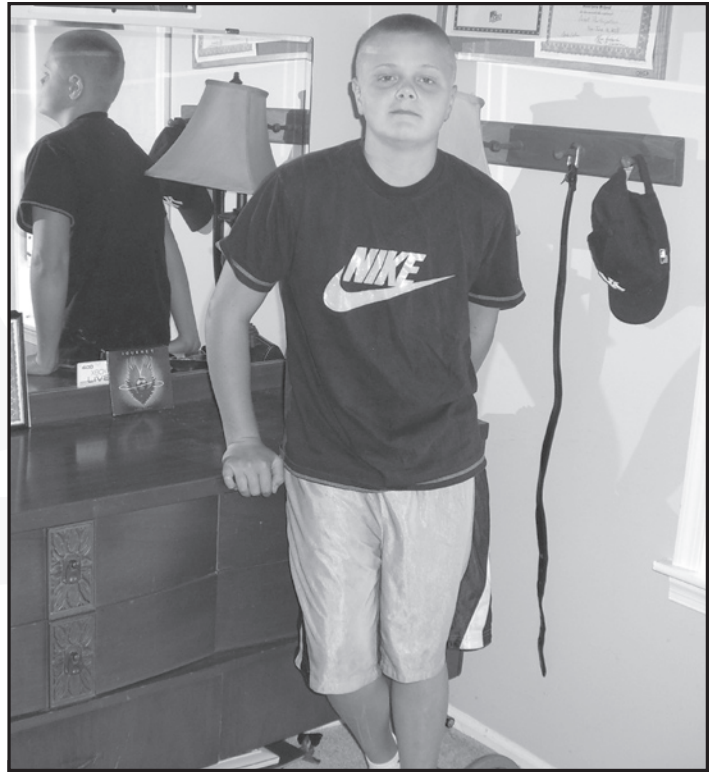
James provides them with support and counseling, and Southern Regional Director Laurie Ehrlich provides a monthly delivery of groceries as well as gift cards and telephone cards in order to offset some of their living expenses.

**Mark's family was forced out of their home due to a house fire.** Almost everything in their home was ruined. They quickly had to find another place to live, and settled in Morganville, where they are renting. Although it is a nice townhouse, Mark's mom confided in their Caseworker, Amy O'Connell, that the place was totally empty. Amy knew that they did not have much money to furnish their new home.

When Amy found out that Eastern Regional Director Joann Passantino had a donor who was looking for a family that needed furniture, she responded immediately, hoping to be the first to take advantage of this offer for Mark's family. The one missing component was transportation. The donor was offering a sofa, chair, dresser, and some other odd pieces. Amy and her husband volunteered to drive to South Plainfield to pick up this furniture in their own truck, and deliver it to the family. In the rain.

Mark's family has been receiving various forms of assistance from ECF, since his diagnosis at the age of two, including grocery deliveries, holiday gifts, and more recently a brand new vacuum cleaner. It's been ten years, and we are delighted to report that he is doing very well. His family is once again receiving groceries from the Eastern Regional Center to help them get back on their feet.

*These real stories illustrate the tremendous needs and challenges faced by ECF families. Where we go from here depends on you. We are committed to helping each and every family that needs our assistance, but we simply cannot do it without the help of caring people like you.*



*Mark with his new dresser*

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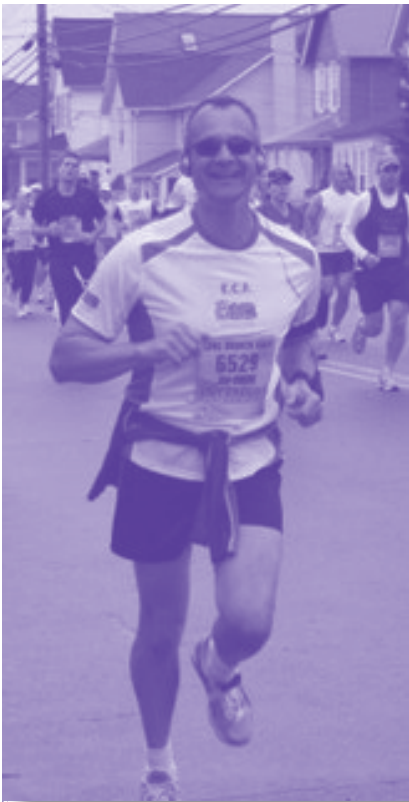
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MOST BLESSED SACRAMENT CHURCH  
MS. JOANNE RAMIREZ  
MR. & MRS. RICK STAMMERJOHANN  
MR. ROGER TAILLON  
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MR. JOSEPH TRAFICANTE  
MR. & MRS. ROBERT C. TRUHAN  
MR. ROBERT WEINER  
MR. & MRS. FRANKLIN YEICH



## Jim Cirone Runs NJ Marathon for ECF

**T**his year's New Jersey Marathon took place from May 1 - 3, in Long Branch. Not only was ECF designated as one of the beneficiaries, but we also had very special representation there. Volunteer Jim Cirone, who is a cancer survivor, donned an ECF tee-shirt and ran a half-marathon

despite his treatment some years ago for Ewing's Sarcoma in his left foot.

In Jim's words, "I had radiation, 18 months of chemotherapy and surgery, and was fortunate that they were able to take out the effected bones and save my foot. It was one of the first times they tried limb salvaging surgery and I was very fortunate that it worked. Running the marathon is a great experience to see some old guy (I'm now 43) who's basically living a normal life and competing in such a physical event."

Jim and his wife, Clare, have been ECF volunteers and donors for many years. They became involved when Clare read about the Charity Ball in her local newspaper, and decided to attend. She is an active volunteer at the Eastern Regional Center, working on the Birthday Club for ECF kids and their siblings, and delivering groceries to families.

We are grateful to Jim and Clare, and we are especially proud of Jim, and thank him for promoting ECF. Most of all, we wish him continued good health.

And thank you, too, to Art Castellano and all the folks at the New Jersey Marathon for picking ECF as a recipient. We are also grateful to Scott Goldman at Optimum Benefits, Inc. in Wall ([www.optimumbenefitsinc.com](http://www.optimumbenefitsinc.com)), for sponsoring ECF with an advertisement, and to ECF Board member Michael Kaufman and Cox Printers in Linden ([www.coxprinters.com](http://www.coxprinters.com)) for marketing ECF through the distribution of flyers to the participants of this event.

## ECF Welcomes Communications Intern Carly Biada



*"My name is Carly Biada and I am currently an intern at ECF's Southern Regional Center. I am going into my senior year of college this fall and will be graduating with my B.A. Degree in Communication Studies in May 2010. I received an e-mail in early May about the Emmanuel Cancer Foundation's Southern Regional Center looking for an intern in the communication's department. The e-mail appealed to me and I quickly responded with interest. After an interview was set up, I was asked to join the ECF team and I couldn't have been happier. I am using this internship experience for college credit and will be spending a total of 120 hours, 15 hours a week, at the Center. However, when my hours are done, I would still love to come back and volunteer my time to do whatever I can to help. Being here has been a great experience and I have met the most kind and most wonderful people I've ever encountered in my life. I am so glad to be here and am blessed to have had this amazing opportunity. Thank you ECF."*

Carol's note: Carly has now officially completed her internship. As part of the ECF team, she contributed a great deal to ECF's marketing and communications strategies, including the design of a Power Point presentation, the creation of a page on Facebook to help reach our younger supporters, and a great deal of marketing assistance to Laurie at the Southern Regional Center.

Laurie's note: This was a very enriching experience for me. I loved having Carly here! I am so happy she is interested in volunteering during her senior year!

# Events



## Blue Knights NJ XV Frost on the Pumpkin Run

Saturday, October 3, 2009

Motorcycle ride through scenic Monmouth County.

<http://blueknights15.com/>



## 12th Annual Celebration of Champions Golf Event

Monday, October 5, 2009

Play a round of golf at one of NJ's premiere courses.

Included are lunch, dinner and auction.

**\$325 individual or  
\$1300 foursome**



## Long Branch Columbus Day Parade

Sunday, October 11, 2009

Parade begins at Broadway and Route 36, and continues up Broadway.

Parade begins at 8:00 A.M.

Enter your float, sponsor the event, or just come and watch.

**Free admission**



## Celebrate Italian Style!

Friday, October 16, 2009

6:30 P.M. – 10:30 P.M.

RiverWinds Community Center,  
West Deptford, NJ

Dinner, auction, dancing and good Italian fun.

**\$45 per ticket**



## 9th Annual Charity Ball

Saturday, February 27, 2010

7:00 P.M. - 12:00 A.M.

The Channel Club, Monmouth Beach, NJ

Buffet Dinner and casino night

**Ticket Price TBA**

We  
Remember

*Nicholas, Lisette, Jacob  
Richard, Christian, & Kasey*

They will forever  
be in our hearts

**Go Green! When you are finished reading this edition of Outlook, please consider passing it along to someone you know who might be interested in learning about what we do at ECF.**

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