

About Us

Elijah with Dr. Stacey Rifkin-Zenenberg, D.O. -
Attending Physician, Saint Barnabas Medical
Center and Camp Happy Times
Volunteer Physician

TVF patient, Elijah (EJ)

Age 7

*Diagnosed with Rhabdomyosarcoma at age 6.
Treated at TVF Center at St. Barnabas Medical
Center, Livingston, NJ.*

Elijah's mom, Tracey, describes The Valerie Fund Center where her son was treated as having a "family atmosphere." At The Valerie Fund she found that, "Everyone knows everybody and we were like one big happy family. When one was hurting, we all were hurting. When everyone was there—staff and patients—it felt like a family reunion.

"Everyone at The Valerie Center played a special role during our son's treatment. From the first day we entered those doors—December 30th, 2008—until this very moment, every staff member has touched our lives in a special way. There is Dr. Rifkin who ensured us that she had a bag of tricks if something went wrong. . . Debi who so graciously gave us her cell number when my husband had to give Elijah his first Neupogen shot. . . Rahima who squeezed us into the schedule when Elijah had to come in unexpectedly. . . Dr. Narang who speaks so softly as if nothing ever upsets her. . . Naomi who insured we would have the proper support system outside of The Valerie Center. . . Mr. and Mrs. Stan who volunteer their time to play games and do arts and crafts with EJ, just to see him smile. . . Lynne, Sharon, Kristine, and Laura who helped and comforted him when he had to go through something unpleasant such as a finger stick, blood transfusion, or dressing change, and were so patient and caring with EJ when he simply was not his happiest.

"On January 20, 2010, we came to The Valerie Center for a checkup. Everyone was high-fiving Elijah because his hair was growing back and he had his port removed! That moment brought a tear to my eye because for them it was a milestone but for me, we were getting our lives back."



Our Mission

The Valerie Fund is a not-for-profit organization established in 1976 in memory of nine-year-old Valerie Goldstein by her parents, Ed and Sue. The Valerie Fund's mission is to provide support for the comprehensive health care of children with cancer and blood disorders.

Our Impact

Families turn to The Valerie Fund Children's Centers because of the unique combination of medical care, counseling, and other services they provide. Our Children's Centers comprise the largest network of healthcare facilities for children with cancer and blood disorders in New Jersey, and one of the largest in the nation. We host over 25,000 patient visits each year.

What Sets Us Apart

Repeatedly, patients and their families tell us they know their experience with childhood illness would have been even more difficult and traumatic had they been treated somewhere other than through The Valerie Fund. Several features distinguish us from other pediatric treatment facilities

- Our centers are **close to home**. Today there are seven Valerie Fund Children's Centers for Cancer and Blood Disorders located in major hospitals in New Jersey, New York, and the Philadelphia area providing caring, comprehensive, state-of-the-art outpatient health care to about 5,000 children each year. This network means that sick children are able to receive care close to their homes. Before The Valerie Fund, many children—such as Valerie Goldstein—had to travel long distances because the treatment they needed was available only at major medical facilities located in large cities.
- We treat **the whole patient**. At The Valerie Fund Centers, patients receive far more than treatment for their physical illnesses. Our philosophy is that to truly heal children we must treat their emotional, social, and developmental needs, as well as their medical needs.
- We care for **the entire family**. Childhood disease strikes not only the child, but the entire family. When a child is a patient at a Valerie Fund Center, a staff of social workers, counselors, psychologists, and child-life specialists enfold the child and the family in a blanket of ongoing, individualized care. We firmly believe this approach is the most effective way to fight childhood disease.



At The Valerie Fund Children's Centers

Child Life Centers: The Child Life Center at each of The Valerie Fund Children's Centers features a playroom stocked with toys and other therapeutic items designed to help children learn about their illness through play, as well as games and other diversions purely for entertainment. The playroom setting allows for better communication between The Valerie Fund Center staff and the children. Each Child Life Center is decorated to be a warm, comforting, home-like environment.

Child Life Specialists: Child life specialists are professionally trained to help children and their families overcome stressful, challenging life events—such as illness—using play, education, and creative activities that facilitate expression of thoughts and emotions. When age-appropriate techniques are used with children they heal more quickly and cope better with pain and fear.

Social Work Services: Social workers at The Valerie Fund Centers provide patients and their families with support and counseling both during and after treatment. They prepare families for what lies ahead, as well as how to deal with social, emotional, and developmental issues. In addition, social workers act as liaisons with schools, and provide information and assistance for dealing with financial matters such as insurance.

Resource Centers: The Family and Patient Resource Center at each Valerie Fund Center features a comprehensive, multi-lingual library of educational materials such as videos, medical teaching dolls, computer software, and workbooks—all geared to help children and families understand their illness and treatment.

TVF patient, Amber

Age 15

*Diagnosed with osteosarcoma at age 14.
Treated at TVF Center at Newark Beth Israel
Medical Center, Newark, NJ.*

Amber thinks “the way patients and their families experience illness and treatment at The Valerie Fund is unique because the facility is family oriented.”

Like many of our patients, Amber developed special, close relationships with many of the staff members at the Center like Shari, a nurse practitioner, and Christina, her social worker. Amber's chemotherapy was administered as an inpatient procedure, meaning that during her course of treatment she was in the hospital for three to four days every week. Because her parents could not stay with her in the hospital, Christina tried to fill the gap and visit with Amber as often as possible. “We enjoyed playing games, discussing her interests, and surfing the Internet,” says Christina. Amber appreciated Christina's companionship, as well as the way she encouraged Amber to express her feelings. It was important to Amber to know that “it's okay to cry and be scared.”



Amber with Christina Rua, MSW, LSW - Newark Beth Israel

At The Valerie Fund Children's Centers

Support Groups: Support groups provide close contact with other children who are coping with the same disease, in a familiar, comfortable, child-friendly setting. Under the guidance of a trained professional, children are able to share and learn from their peers who have been through similar experiences. Groups provide a safe haven where they feel free and comfortable to express their feelings and thoughts.

Sibling Workshops: Siblings of seriously ill children often feel overlooked by parents and family consumed with the care of a sick brother or sister. This psycho-social program for siblings was adopted by The Valerie Fund as a way for these siblings to obtain peer support and education within a relaxed, recreational context. Through role play and group counseling, siblings share common joys and concerns; learn more about the implications of their brothers' or sisters' diseases and the special needs associated with them; and address their own feelings of guilt, embarrassment, shame, loneliness, and resentment. They also take part in activities that are purely recreational.

School Re-Entry Program: Many children have difficulty socializing and keeping up with schoolwork after they become sick. Often schoolmates do not know how to relate to their friend who is ill. Each Center's School Re-entry Program helps children to successfully return to school after diagnosis or treatment by educating classmates and teachers in the classroom before the child returns.

Sickle Cell Program: Each of The Valerie Fund Children's Centers treats sickle cell patients from infancy, which is when most children are diagnosed, until they become young adults at age 21. The program at our Newark Beth Israel Center is the largest in the state of New Jersey, with about 450 patients. Because there is no cure for sickle cell disease, many patients will come to the same center for 20 years, developing strong bonds with their caregivers there and even other patients.

TVF patients, Tiara and Zyon

Ages 17 years and 7 months

Both diagnosed with sickle cell disease. Treated at TVF Center at Newark Beth Israel Medical Center, Newark, NJ.

Being treated at The Valerie Fund is different than being treated at other facilities, says Tiara "because it's like a big family. The people are nice and my family and I feel comfortable." When asked to name some people who were especially supportive or comforting, Tiara said, "Christina gave me support throughout my pregnancy; Dr. Kam has been so good to me and my whole family since I was a baby; and Kathy makes me feel really good whenever I come to the Center." Tiara says she has seen many instances that illustrate The Valerie Fund's philosophy that medical treatment is most effective when you treat the whole patient and the whole family. "Throughout everything," says Tiara, "The Valerie Fund has been there."



Tiara and Zyon

Late Effects

Forty or fifty years ago, the survival rate for childhood cancer was around 20 to 30%. Today the cure rate is approaching 80%. It's a dream come true: the first generation of childhood cancer survivors. Long after their treatment has ended, survivors of childhood cancer continue to face serious health, developmental, and emotional challenges—known as late effects—resulting from their illness and the drugs used to cure them. Because this is a new medical phenomenon, “regular” doctors don’t know what to look for when a patient says, “I’m a survivor of childhood cancer.”

Thanks to a newly formed collaboration, former and current patients of The Valerie Fund now have favored access to the cutting edge Valerie Fund/CINJ LITE (**L**ong-term, **I**nformation, **T**reatment effects, and **E**valuation) Program of The Cancer Institute of New Jersey (CINJ), the state’s first and only National Cancer Institute-designated Comprehensive Cancer Center. Staffed by professionals who specialize in late effects care, LITE allows us to provide a complete continuum of care for our survivors in order to provide them with the best possible quality of life. An educational component teaches survivors to self-advocate, a skill they will need often throughout their lives in areas such as covering the insurance gap, identifying scholarships for higher education, understanding rights related to employment and cancer-related disabilities and transitioning to adult care.



Jessica with Dr. Margaret Masterson, Director of The Valerie Fund CINJ/LITE program

TVF patient, Jessica

Age 22

Diagnosed with acute lymphoblastic leukemia (ALL) at age 4. Followed at The Valerie Fund Centers at St. Barnabas Medical Center, Livingston, NJ and Newark Beth Israel Medical Center, Newark, NJ. Jessica is currently a patient in The Valerie Fund/CINJ LITE Program.

When Jessica was diagnosed at the age of four with ALL, the doctors told her parents she had a 10% chance of survival. For the next four years, her medical regimen included chemotherapy, radiation, spinal taps and blood transfusions. Several discs in her lower back fractured because of the spinal taps. At the time, the medical community was still learning what it took to cure children and so many of Jessica’s treatments were given at adult-level dosages to help ensure her survival. Through The Valerie Fund Center, she was able to participate in clinical trials that may have saved her life, while adding to the body of research that would produce new treatment protocols. Jessica has been in remission for about 14 years and is considered cured, however she suffers from late effects of her cancer treatments.

“Ever since I’m off treatment, I don’t feel well.” Jessica suffers from migraines, gastrointestinal disturbances, extremely dry skin that can itch or burn and carpal tunnel syndrome in both of her arms.

“My memory is so bad that I tend to repeat myself. I feel like I’ve been running a marathon even when I haven’t done much.”

Jessica has been to many doctors but none of them have been able to figure out how to help her. She visited with two doctors and a nurse at The Valerie Fund/CINJ LITE Program a few weeks before her initial consult there. Since meeting with them she believes that they will be able to help her. “It felt warm there—like a Valerie Fund Center. I felt like I was finally in the right place.”

Camp Happy Times

Since its first summer session in 1983, over 3400 children have enjoyed a totally free one-week overnight camping experience at The Valerie Fund's Camp Happy Times. The Valerie Fund provides transportation, meals and on-site medical care at Camp Happy Times each summer to nearly 200 children at the 220-acre Tyler Hill Camp in Wayne County, Pennsylvania.

The hallmark of the Camp Happy Times experience is that while they are there, the campers do not feel self-conscious about their illness. Campers consistently revel in the fact that they don't have to explain their disease to their fellow campers.

The mission of Camp Happy Times is to promote friendship, independence, and a spirit of cooperation for cancer patients and survivors. Camp is a recreationally therapeutic environment featuring all of the typical camp activities that engage participants while building self-esteem, confidence, trust, and friendship.

Lifelong bonds are established between kids who all know what it's like to be sick.

Staff and counselors are all volunteers. More than 30 counselors are former campers and return annually. Medical staff, social workers, and child life specialists are on site and available 24 hours a day, every day.



CHT counselor and former camper, Mark Coxson

Age 36

Diagnosed with Osteogenic sarcoma at age 12. Attended Camp Happy Times 1984 - 1988.

When asked why he has volunteered as a counselor at Camp Happy Times for a week every summer since 2002, Mark's response is quick and to the point: "It's my turn. You have to give back to those who gave to you."

Mark was a camper at CHT for five years, starting with the second year

that camp was open. As a camper his favorite counselor was a young man named Jeff because, "You knew he'd do something funny." As an adult, says Mark, "I wanted to be that crazy counselor—and I am!" Campers expect to see Mark at flagpole each morning in some outlandish getup, and he's more than

happy to oblige, appearing each day in different outfits such as pink footy pajamas or a Captain America costume. He arrives at camp each summer with his Ford Explorer and an attached trailer brimming with toys and hats. "The key is to act like you're eight, but remember they are kids and need guidance," says Mark. He comes on stage in a different outfit between each act of the talent show, even dressing up as a girl, because, "All that matters is to make the kids laugh. It's all about being goofy." Mark also holds a fundraiser every year at the bar where he works, raising thousands of dollars for CHT.

Although the physical amenities at camp have improved dramatically since Mark's days as a camper, the essence of camp has remained the same: all the kids support one another. He remembers one camper, Justin, who had spinal meningitis as well as cancer. He could not do anything for himself and needed 24-hour supervision. True to the CHT spirit, all the kids loved Justin and would go out of their way to come over to talk to him and high-five him. "This," says Mark, "is what camp is all about."



Additional Programs, Partnerships, and Collaborations

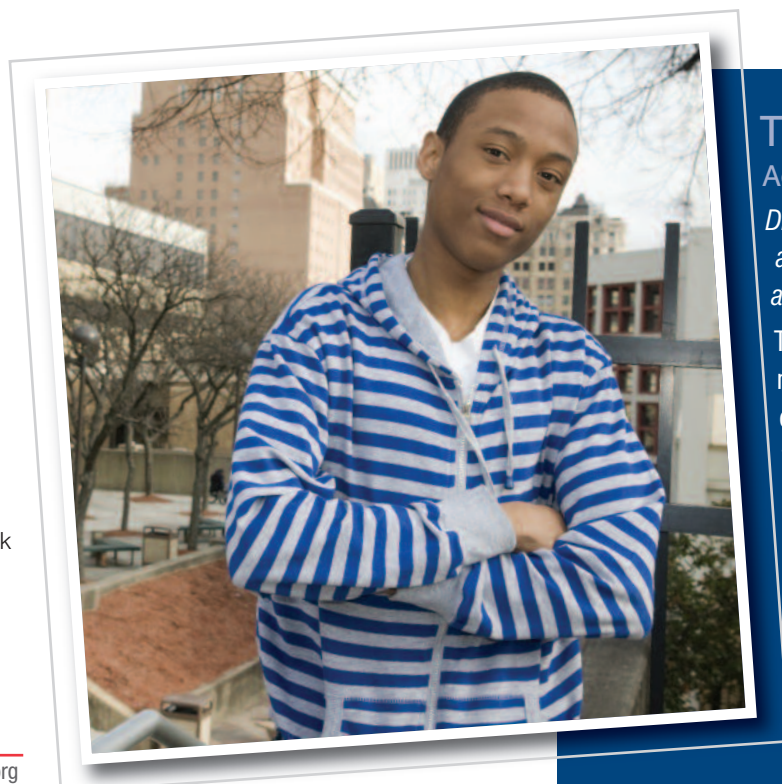
Scholarship Program: Since 2007, The Valerie Fund's scholarship program has awarded over \$50,000 of financial support to 60 children who are treated at TVF Centers or attend Camp Happy Times who are attending a post secondary institution to further their education. Scholarships help current and former patients and campers attend universities, colleges, community colleges and trade schools.

Transportation Program: For many families who have only one car or rely on public transportation for all of their needs, getting to and from treatment can pose a serious challenge. A van dedicated to patients at the St. Barnabas Valerie Fund Center, which is sometimes used for Valerie Fund patients at Newark Beth Israel as well, ensures that families have safe reliable transportation so that they can maintain their treatment schedules. It also ensures that patients have privacy and comfort after a day of a chemotherapy or an outpatient medical procedure. In addition, a small transportation fund is available to cover costs for patients at the other centers who have no viable means of transportation.

Flashes of Hope: Flashes of Hope[®] (FOH) is a Cleveland-based non-profit organization dedicated to creating uplifting photographic portraits of children fighting cancer and other life-threatening illnesses. Their mission is to help sick children feel better about their changing appearance by celebrating it! The photos are free of charge to the families. In spring 2008, FOH opened a Valerie Fund chapter. Rotating among TVF Centers at St. Barnabas, Newark Beth Israel, Morristown, and Overlook, there is a FOH photo shoot at one Valerie Fund location about once a month.

Hematology Camps: Children with sickle cell disease, hemophilia and other blood disorders have special medical needs that require 24-hour access to highly specialized care in the case of an emergency. Staff at The Valerie Fund Children's Centers enroll dozens of hematology patients in specialized overnight hematology summer camps located throughout the Northeast. The Valerie Fund arranges long-distance round-trip transportation just as it does for children attending Camp Happy Times.

Sickle Cell Initiative: In recognition of its Sickle Cell Initiative, The Valerie Fund was invited to participate in a new sickle cell project called the Central Northern New Jersey Sickle Cell Network. Funded by a government grant through the U.S. Department of Health and Human Services and led by hematologists at Newark Beth Israel Medical Center, The Valerie Fund will work together with the medical and lay community to preserve the health of sickle cell patients by increasing access to medical care and expanding education.



TVF patient, Ty'Rell

Age 20

Diagnosed with sickle cell disease at birth. Treated at TVF Center at St. Barnabas Medical Center, Livingston, NJ. He currently attends Essex County College and received a TVF scholarship.

Ty'Rell has been battling sickle cell disease his entire life. That means that, unfortunately, he's dealt with more than his fair share of hospital settings and medical personnel. He says, "The way that the nurses and doctors treat their patients [at The Valerie Fund] is different than any other hospital I have seen. They seem like they actually care and don't try to rush through the time they spend with patients. "There are plenty of ways that The Valerie Fund helps out and treats patients' minds, hearts, and bodies. One example is all of the volunteers that help out. They don't get paid, but it makes them so happy when they put smiles on their patients' faces."

Ty'Rell at Essex County College, Newark

Giving and Receiving at The Valerie Fund

A gift of time is priceless. Without volunteers, The Valerie Fund would only be able to accomplish a fraction of what we do to support sick children and their families.



TVF patient Leo with Stan Beck

Take Ethel Sharenow, for example, who works behind the scenes helping to manage hundreds of patient records in order to support the work of the clinicians who treat the kids.

Or Stan and Jean Beck, surrogate grandparents to countless children, who have played with trains

and dolls, read Dr. Seuss stories aloud, and held tea parties in a Valerie Fund Children's Center playroom three to four days a week since 1999. Because of them, kids like Leo can't wait to come in for the next appointment.

And finally, there are the hundreds of children and adults who bring the message of The Valerie Fund into their communities and workplaces to raise thousands of dollars each year so that the bravest children we know will have the hope and healing that they deserve.

TVF volunteer and donor, Ethel

Volunteer since 2008 at St. Barnabas Medical Center, Livingston, NJ.

All it took was one visit to The Valerie Fund Center at St. Barnabas and Ethel was hooked. "It just didn't seem enough to donate money," she says. "I wanted to be a part of the Center." And just like that TVF gained a new donor and volunteer.

Ethel will never forget the day she saw "an invitation from one of our patients inviting everyone to a party to celebrate his last chemotherapy treatment. What a happy day for him!" While there are many worthy charities with which Ethel could have become involved, TVF "serves our local community. I couldn't believe that here it was, in my own backyard, and I didn't know it existed. I would like people in the communities where the Centers are located to be aware of all the wonderful things they do."

Ethel is impressed with "how caring all the people are who work at the Centers, not only to the patients,

but also to the families." The importance of TVF is reinforced every week when she volunteers. "People say, 'I don't know how you do it.' But what they don't understand is that the kids come in smiling. The amount of good that happens in a Valerie Fund Center is immeasurable."

TVF patient, Sierra

Age 16

Diagnosed with acute lymphoblastic leukemia (ALL) at ages 5, 9, and 16. Treated at TVF Center at St. Barnabas Medical Center, Livingston, NJ.

"I think the volunteers help take the kids' minds off all of the medical stuff like the shots, blood draws, and other medical procedures. They comfort the little kids around the center and play with them, and do activities with the older kids. They help you feel comfortable and like you are not in a hospital. It makes the kids feel better to have someone to talk to.

"Jean and Stan have been there ever since I can remember. I was treated when I was 5 and then again when I was 9, and they were always in the playroom, trying to cheer me up and play with me so I would feel better about my treatments. Now I am 16 years old and I am in treatment again, which will last for two years. I go to the Center two to three times a week and it is great to see Jean and Stan there because it is like seeing friends.

"I would tell anyone who is thinking about being a Valerie Fund volunteer – if you would give up one day of your week a child might remember you for life."



Ethel Sharenow with Sierra

Locations

Our Eight Locations

- Children’s Hospital of New Jersey at Newark Beth Israel Medical Center
- Children’s Hospital of Philadelphia, NJ Section of Hematology/Oncology, Specialty Care Center
- Morristown Memorial Hospital Goryeb Children’s Hospital
- NewYork-Presbyterian Morgan Stanley Children’s Hospital, Columbia University Medical Center
- Overlook Hospital
- Saint Barnabas Medical Center
- The Children’s Hospital at Monmouth Medical Center
- The Valerie Fund/CINJ LITE Program at the Cancer Institute of New Jersey



Jake with Beth Baratz, MS, Certified Child Life Specialist — Monmouth

TVF patient, Jake Age 14

Diagnosed with acute lymphoblastic leukemia (ALL) at age 6; relapsed at age 12. Treated at TVF Center at The Children’s Hospital at Monmouth Medical Center, Long Branch, NJ.

Jake has no doubt that The Valerie Fund was the best possible place to be treated.

He says, “The Valerie Fund staff is the best! They treat you like a king!” He has happy memories, even though he was so sick. For instance, says Jake, “I had fun skateboarding down the ramp to the pediatric floor on my IV pole. I enjoyed spending time with the staff at the picnics and Christmas parties—not just at the hospital.” “You become part of The Valerie Fund family,” adds Jake. “Everyone played a special part in helping me get through this horrible disease, especially Beth, the child life specialist. They treated my whole family, not just me, and included my family in all activities. My parents could speak to anyone on the staff whenever they needed to. We laughed, cried, and shared many happy and sad moments—they were my new family.”

TVF patient, Jessica

Age 12

Diagnosed with Medulloblastoma at age 11. Treated at TVF Center at St. Barnabas Medical Center, Livingston, NJ.

“The Valerie Center is truly a home away from home,” says Jessica’s sister, Cassandra. “The doctors and staff get to know the patient as a person. Because of the welcoming and warm environment, the children look forward to coming and getting treated.”

The Valerie Fund prides itself on treating the whole patient—mind and heart as well as body. Jessica is able to cite many examples of this philosophy in action. She says, “Dr. Rifkin makes me laugh when she says, ‘Later gator, in a while crocodile.’ Lynne makes me laugh when I am sad, and Laura makes me feel important when I feel like I am nothing.”

Because of this compassion and attention to all of Jessica’s needs, not just her medical treatment, “Jessica feels like a person,” says Cassandra. “It is so easy for Jessica to get caught up in her illness when at home. When she comes to The Valerie Center, she gets treated as a whole individual and not as a ‘tumor.’” Her experiences at The Valerie Fund are an important affirmation for Jessica. As she says, “If the doctors treat me as a ‘normal’ kid, then I must be a normal kid!”



Jessica with Debi Neretich, RN, APN, CPON — St. Barnabas