FALL 2024

ECFvoice

THE NEWSLETTER OF THE EMMANUEL CANCER FOUNDATION

Lila: An Emotional Journey

LILA'S FIRST EVER HAIR CUT WAS HER HEAD BEING SHAVED DURING CHEMO. Her leukeumia was discovered when she was three years old. Lila went from a healthy and energetic little girl to suddenly being incredibly sick.

She began a three-year treatment plan, suffering nausea, belly pain, muscle and nerve damage, and pain in her fingers and toes. Steroids caused her to be moody, hungry, weak and extremely swollen.

Lila had difficulty understanding that she was ill and could not go to school. *"We explained to her that her blood is sick, and she needs medicine to make her better,"* said her mom. They read Lila books about cancer, chemo, and hair loss to help her understand what she was going through.

Lila's dad tried to stay outwardly strong but struggled with watching his daughter go through so much pain and suffering. Her 16 year old sister Madison was sad she couldn't do anything to fix her little sister's cancer. Lila's mom felt similarly. *"I feel like I failed to protect her even though I know I couldn't,"* she said. The hospital recommended they reach out to the Emmanuel Cancer Foundation for support.

> *"ECF provided us with someone to talk to and gave us monthly food donations and gift cards. We are so grateful for their help."*
>
> LILA'S MOM

Lila's parents describe her as strong and brave, but also funny, loving and independent. She loves to paint, ride her bike and her Minnie Mouse scooter, and run around outside. Her dream is to go back to school and to meet her favorite character Minnie Mouse.

"This whole journey has been a wild one," her mom says. *"It's been an emotional journey of grief, sadness, anger…. and happiness because she is still here and fighting."*

We can help these beautiful families because of YOU! Thank You!!!!

JABARI: A Young Optimist with a Rare Cancer

WHEN JABARI WAS IN THE HOSPITAL, his sweet and caring nature made him a favorite among the staff. The nurses on the floor would fight over who would get to have him on their shift. His joyful personality shines, despite all he has gone through.

When Jabari was 13, he was diagnosed with synovial sarcoma, a rare and aggressive cancer typically found in the joints. In Jabari's case, the disease attacked his throat, which became so sore he could barely eat. His mom Asiah took him multiple times to the primary care doctor and the emergency room. They sent him home with antibiotics that did nothing to alleviate his pain. A specialist thought it was his tonsils and scheduled Jabari for surgery. Asiah knew in her heart it was something more. Her child was suffering too much.

Right before the tonsil surgery, Asiah took him to a different hospital where doctors discovered a mass in his throat that left only a tiny amount of space for air to get through. Jabari was precariously close to suffocating and was immediately taken to the ICU. Surgery removed 80 percent of the tumor, preserving his voice box.

A year of chemo and radiation followed, burning his throat, making him sick, and keeping him out of the school that he loved. Unfortunately, after a few months the tumor grew back. In another attempt to preserve Jabari's voice box, doctors unsuccessfully tried immunotherapy. Ultimately, he had his voice box removed, eliminating the tumor 100 percent. Jabari was the youngest person the doctors had ever seen undergo this surgery. He now uses texting to communicate.

During this ordeal, not only did Asiah lose her job, but she suffered the deaths of both her parents. Though she has a big family that lives nearby, her father was her "rock" and had helped out with Jabari's hospital stays and caring for his younger sister Mia.

Asiah says she gets through by "just keeping going" even when her body wants to break down. Despite facing immense personal and financial challenges, Asiah has shown unwavering dedication to her family, staying by Jabari's side in the hospital, using her creative talents to earn money, and doing extensive medical research to stay informed to advocate for her son. She calls herself a "mama bear."

Despite her strength, Asiah was grateful for ECF's support.

> *"You guys are amazing! Our ECF Caseworker ViAnna is very, very supportive."*
>
> ASIAH, JABARI'S MOM

ECF also delivered groceries and helped with bills and the steep costs of driving Jabari back and forth to treatment in New York City.

Known for his optimism, Jabari doesn't let his situation get him down. Even with a tracheotomy, he was happy to be at school. He didn't let it alter how he felt about himself, and his friends have been accepting and supportive. He loves building things and wants to be an engineer. A lover of all things Marvel, he crafts his own costumes and hopes to one day get a 3-D printer to enhance his costume making.

SHANE: A New Normal

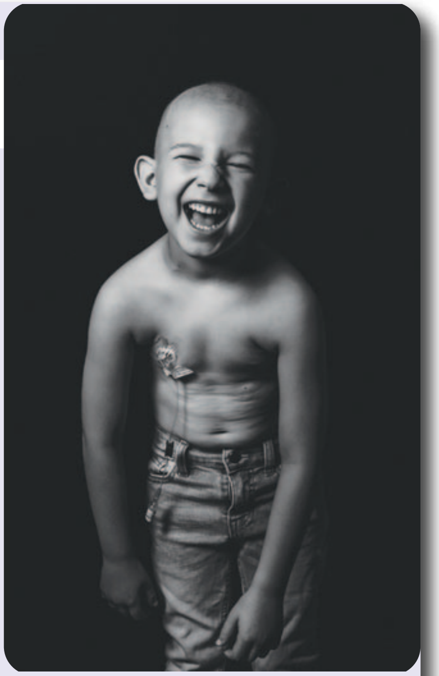
IT TOOK EIGHT MONTHS OF DOCTOR VISITS AND TESTING, four bone marrow biopsies, two second opinions, and countless hospital stays to diagnose six year old Shane with leukemia. The treatment he required was equally lengthy, requiring 10 months of intensive chemo and 20 spinal taps.

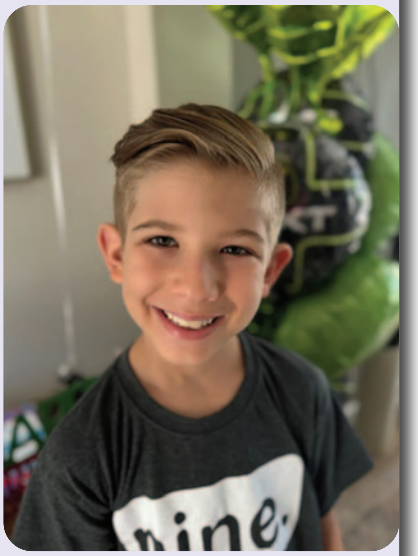
Little Shane suffered grueling side effects — pancreatitis, appendicitis, and debilitating mouth sores. Daily he was fatigued and nauseous and needed physical and occupational therapy to tackle his painful neuropathy. He experienced an extensive blood clot in his brain that left a permanent blockage that restricted his daily activities. *"It has been incredibly hard as a parent to watch Shane endure these side effects and to know that cancer has taken so much from him,"* said his mom Michelle.

During treatment, Shane began exhibiting extreme behavioral issues related to his treatment and how it was preventing him from just being a kid.

> *"Because we were stuck in a hospital room for months, we had to choose joy each day."*
>
> MICHELE, SHANE'S MOM

Individualized therapy was not working. *"ECF provided us with an amazing in-home family caseworker who impacted our family as a whole,"* said Michelle. *"Her techniques and recommendations have not only completely eliminated Shane's behavioral issues, but have given us tools to use to help him and his younger sister navigate our new normal."* ECF also delivers monthly groceries and birthday gifts.





Shane's mom says this significantly reduces their monthly food bills and helps them spend less time grocery shopping and more time together. *"During Shane's birthday month he received gifts and party supplies,"* she added. *"Each month there is also a book and a toy for each child in our food delivery."*

Now nine years old, Shane has two more cycles of long-term maintenance chemotherapy. His mom describes her son as intelligent, sweet and funny. He loves reading, playing football and learning about the game, and writing and illustrating comics. His goal for the future is to become an NFL player and have a house on Long Beach Island.

His mom says Shane has been an active participant in all of his medical appointments and has even weighed in on medical decisions. Despite resilience beyond his years, Shane still struggles with fear and worry. *"He has to be reminded just how brave he is,"* says Michelle. *"As a family we were thrown into this world of childhood cancer and take it day by day, sometimes minute by minute."*

Your kindness changes these families' lives.

upcoming EVENTS

BOCCE BALL-A-PALOOZA
September 22, 2024

SOUTHERN REGION
GOLF OUTING
September 23, 2024

24TH ANNUAL CRYSTAL GALA
March 1, 2025

14TH ANNUAL CHARITY BASH
June 11, 2025

ECF IS GRATEFUL TO THE FOLLOWING FOUNDATIONS AND CORPORATIONS THAT PROVIDED RECENT GRANT SUPPORT:

Alfred N. Sanzari Family Foundation
Bastazo, Inc
Catholic Human Services Foundation
Chik-fil-A Oakhurst
Citizens Bank
Dennis Drohan Memorial Golf Outing
Holmdel Fire Company
JJC Memorial Golf Tournament
Johnson & Johnson Family Companies
MSO, Inc.
Northfield Bank
St. Mary Advocates, Inc.
Student Movement Against Cancer
The Mariner Foundation
United Roosevelt Savings Bank
Wawa, Inc.
Westfield Service League

Thank You!

Make your legacy a future of comfort and care for NJ children with cancer.

By giving to ECF through your will, trust or other financial plan, you can ensure that kids with cancer and their families have what they need today, tomorrow and into the future. When you join our **"Future of Care Legacy Circle,"** you receive a framed work of art from one of our talented ECF kids, a token of our — and their — gratitude for your generosity. For more information, contact **Victoria** at **908-322-4323 ext. 15** or **varonoff@emmanuelcancer.org**.

Surrounded by his mom, brother and hospital staff, Liam rang the "No More Chemo" bell after 14 rounds! We are so happy for you Liam after all you have been through.

CONTACT US

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