



PROGRESS UPDATE SPRING 2022

Cory's Crusaders

The
Dana-Farber
Campaign

Defy Cancer





**Joseph Chabot, MS, Pediatric
Resource Program Director**

Introduction

A cancer diagnosis brings significant challenges for children and their families. In an instant, their days center around adjusting to a life-threatening illness, juggling appointments, and navigating insurance, while often carrying a heavy financial and psychological burden.

The need for patient support services is on the rise. New and promising cancer treatment regimens and improved early detection methods are contributing to the growing patient population here and across the nation. And yet while families' financial needs have increased, many pandemic relief programs have expired, and assistance from standard government programs does not cover the costs that come with frequent clinic visits and prolonged hospitalizations. These out-of-pocket expenses include transportation, money for meals in Boston, and accommodations for families from afar. Families struggle to cover these new costs and keep up with their essential household expenses—rent or mortgage, groceries, utilities—as parents' work hours and income are often drastically reduced to care for their sick child.

Dana-Farber researchers have found that one in five children with cancer experience housing, food, or utility insecurity at the time of their diagnosis. These children face significantly inferior outcomes from diagnosis, through treatment, and into survivorship. As we seek to improve childhood cancer outcomes, these unmet needs must be addressed just as vigorously as medical needs in order for children to survive and thrive.

The generosity of Cory's Crusaders has been vital in helping Dana-Farber Cancer Institute meet these critical needs through our Pediatric Resource Program. Our program is truly an important part of treatment for many of our patients. Thank you for sustaining our efforts to ensure that all children—regardless of their economic situation—can receive our world-class care. We are deeply grateful for your dedication to this important program.

Joseph Chabot, MS, Pediatric Resource Program Director

TIMELY ASSISTANCE MAKES A GREATER IMPACT

Thanks to your incredible generosity, the Pediatric Resource Program was able to provide more direct financial assistance to patient families than ever before. Below are some examples of the lives that have been touched thanks to philanthropic giving.

Eric

In August 2021, 6-month-old Eric, from New Hampshire, was admitted to the hospital and diagnosed with a brain tumor called nodular desmoplastic medulloblastoma. Except for one day at home, Eric has spent his first seven months of treatment hospitalized in Boston. Eric lives with his parents, Amy, a first-grade teacher, and Dan, a physical education teacher. Amy has been on leave since Eric was admitted to the hospital and quickly exhausted her paid leave time. The family was soon struggling to keep up with essential household expenses, including their monthly mortgage payment. Patient assistance funds covered several mortgage payments for Amy and Dan, giving them some much needed breathing room.

Jessica

In December 2021, 8-year-old Jessica from northern Maine was diagnosed with myelodysplastic syndrome, a blood disorder that can develop into leukemia. She was soon transferred to Dana-Farber, almost six hours away from the family's home. For the next year, Jessica's care involved frequent Jimmy Fund Clinic visits and several long hospital admissions, including an admission for a stem cell transplant.

Jessica and her two young siblings live with their parents, Marie and David. Marie, a nurse, had recently finished treatment for breast cancer and was about to return to work when Jessica was diagnosed. David, a sales representative for a heating company, did his best to work his normal hours, but the family's finances were soon under great strain. Not only did the family suffer from Marie's lost income, but they were facing thousands of dollars in new out-of-pocket expenses related to Jessica's care in Boston. Dana-Farber was able to provide the family with regular gift card stipends to help with gas and meals in Boston, along with several grants to help the family keep up with their essential household expenses in Maine.

Alli

Alli, age 18, lives with her parents, Laurie and Dan, in central Massachusetts. In July 2021, Alli was diagnosed with a rare and difficult-to-treat brain tumor. Since starting treatment, her care has involved multiple surgeries, radiation therapy, and chemotherapy. In late 2021, she began a long hospital admission that included several weeks in the ICU.

Laurie is a self-employed account relationship manager, and she has been unable to work due to Alli's illness. Although Laurie was receiving unemployment benefits, they expired, and Dan, who was working two full-time jobs, had to leave one of his positions due to Alli's required care.

Alli was ill for several months prior to her brain tumor diagnosis, and in the past year, the family has spent thousands of dollars on out-of-pocket expenses related to her care. The family is struggling to keep up with their essential household expenses, including their monthly mortgage payment. Patient assistance funds have helped the family pay their mortgage, as well as keep gas in their car and food on their table.

Charlie

In June 2021, 5-year-old Charlie, from Worcester County, was urgently admitted to the hospital and diagnosed with a malignant brain tumor. Charlie started a treatment regimen that is expected last at least a year, and he spent most of his first four months of treatment hospitalized. As part of his care, he has undergone several surgeries, radiation therapy, and ongoing chemotherapy treatments.

Charlie and his two young sisters live with their parents, Julie and Peter. Julie was working as a special education teacher, but she has been on leave since Charlie's diagnosis. Julie quickly exhausted her paid leave time, which cut the family's household income in half. The family was struggling to keep up with their essential household expenses, especially their mortgage payment. Patient assistance funds helped the family pay their mortgage, allowing them to focus their energy on caring for Charlie.

Diane

Diane, an 8-year-old from Boston, was first treated for a stage IV neuroblastoma in 2018. In 2021, she relapsed and resumed treatment. Her care involved regular hospital admissions for chemoimmunotherapy treatments, along with frequent visits to the Jimmy Fund Clinic. Diane lives with her single mother, Noreen. Diane's initial treatment regimen was long and difficult, and Noreen was just starting to get back on her feet financially

when Diane relapsed. Noreen, who works as a part-time certified nursing assistant, had to reduce her hours due to Diane's relapse and care. The family's only other income was a monthly Social Security disability stipend. Patient assistance funds helped Noreen with a rent payment, easing her anxiety and helping to ensure stable housing for the family.

Ella

Ella, a 9-year-old from central Massachusetts, was first diagnosed with an optic pathway glioma in May 2014. She recently relapsed for the second time and resumed treatment. Ella and two of her siblings live with their parents, Danielle and Phil. Danielle, a self-employed manicurist, had to close her business due to the pandemic, and her unemployment benefits have expired. Phil, a truck driver, is still working, but his income has also suffered due to the pandemic. Patient assistance funds enabled the family to pay their mortgage and helped with gas, tolls, and meal expenses related to Ella's care in Boston.

Diana

Diana, age 18, was diagnosed with Ewing sarcoma in 2016 and subsequently developed therapy-related acute myelogenous leukemia (AML) in 2018. In 2021, she was diagnosed with relapsed AML and had to resume treatment, which included a second stem cell transplant. Diana and her sister, a college student, live with their parents, Eddie and Cathy, in southeastern Massachusetts. Both parents work as certified nursing assistants and have taken a lot of time off work over the years due to Diana's illness and care. By the time Diana had begun treatment for the third time, the family had exhausted their savings, most of their paid time off, and were struggling to make ends meet. Patient assistance funds covered two mortgage payments for the family while Diana was in the midst of her second stem cell transplant admission.



Lilliana Lopera-Jimenez, BS

OVERWHELMING BURDENS EASED WITH COMPASSIONATE CARE

Senior Resource Specialist Lilliana Lopera-Jimenez, BS, who brings 10 years of experience to her role, is an example of the Pediatric Resource Program's dedicated staff. She works with many immigrant families, as well as families from across New England, who are facing significant socioeconomic challenges when they arrive at Dana-Farber. Lopera-Jimenez listens to each family's unique situation to learn more about their most pressing needs—often gas, transportation, and accommodations—and provides them with resources and patient assistance funds to help fill these gaps. She also advocates on behalf of families by providing utility companies with proof of medical hardship, another means of helping to reduce financial strain.

Informed by her own experience as an immigrant from Colombia, Lopera-Jimenez understands the complexities that can arise when dealing with health insurance, immigration issues, language barriers, and cultural differences. When issues such as legal assistance or insurance coverage arise, Lopera-Jimenez acts as a liaison to community resources. For example, if health insurance does not cover certain costs, she works with Dana-Farber's valued community partners specializing in immigrant social services and health insurance to help find a solution.

Finding temporary or long-term housing for patient families is particularly challenging due to tight restrictions and a severe shortage of affordable accommodations—and long waitlists for the few available affordable accommodations are the norm. One of Lopera-Jimenez's recent families—a single Latino father living in Boston with his 16-year-old son—suddenly needed to relocate from an unsafe, overcrowded multifamily apartment when his son relapsed with lymphoma. Disabled due to a work-related injury and still awaiting Social Security benefit approval, the father, whose English language skills are limited, had struggled to find adequate, stable housing. He relied on Lopera-Jimenez to help quickly secure a shelter with its own separate living quarters to accommodate the family so that the son could be safely isolated during his treatment.

Lopera-Jimenez is also assisting a local single mother whose child has relapsed leukemia and is now receiving care at Dana-Farber. Because the mother is unable to read and does not own a car, Lopera-Jimenez has devoted an extraordinary amount of time to help her navigate extensive medical paperwork and coordinate appointments with MassHealth's transportation service.

Lopera-Jimenez is not only adept at identifying and addressing families' various material needs, she is also a significant source of emotional support in the midst of overwhelming stress, particularly for single parents with no built-in support system to share the burden. "We can't solve it all, but we try our best," she said. "The beauty of our role as resource specialists is that we are very focused on helping families get through this, and we let them know that we'll be there for them as much as we can."

The Impact of Your Philanthropy

Through your generous support, Dana-Farber is able to provide vital patient assistance our pediatric patients and their families. Because of you, our team is able to fulfill the "family-centered care" philosophy of Institute founder Dr. Sidney Farber, assuring that the financial needs of our patients and families are met alongside their medical needs. We thank you for your ongoing partnership in this work.

Report written by Jodi Hyer.



The Dana-Farber Campaign

Defy Cancer

In May 2021, Dana-Farber announced **The Dana-Farber Campaign**, our ambitious, multiyear \$2 billion fundraising initiative to prevent, treat, and Defy Cancer by accelerating **revolutionary science, extraordinary care, exceptional expertise, and essential opportunities.**

The people we love the most
can help us to lean on their
courage and stand up again.

support

hope



Dana-Farber Cancer Institute has been the top-ranked cancer hospital in New England by *U.S. News & World Report* for 21 consecutive years, and is the only cancer center in the country ranked in the top 4 for both adult and pediatric cancer programs.



Dana-Farber Cancer Institute was named the #3 cancer center in the world by *Newsweek* in its World's Best Specialized Hospitals ranking.

The Dana-Farber Campaign Defy Cancer



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10% of all designated gifts will support our Faculty Research Fund to advance Dana-Farber's research mission.