

DONTE'S JOURNEY: FROM BAD TO WORSE TO BETTER



Holness family

If you met Donte Holness, your first impression might be that he's a typical 13-year-old. He loves swimming, reading, movies, joking around with his friends, and video games. But a closer look would reveal that this bright eighth-grader is far from "typical" and the journey he and his family have been on the last two years is quite extraordinary.

In spring 2022, Donte, then 11, was experiencing recurring fevers, body aches, and a general sense of fatigue. "Our first thought was maybe he had COVID, but he tested negative," recalls his stepdad, Rich Ward. Urine tests, X-rays, and preliminary bloodwork would follow. But again, no red flags. Still, Donte's mom, Moya Williamson, had an intuition that this was more than a cold or flu. "I felt it in my gut that something was really wrong with my child's body."

It turns out, she was right.

One day, when the family was visiting friends, Donte's walking became so labored and unsteady that he had to be helped to the car. "And five minutes into the ride

home, he was asleep," his mom remembers. "It was just strange. We couldn't make sense of it."

Fortunately, the staff at Hasbro Children's Hospital's Tomorrow Fund Clinic would soon put the puzzle pieces together. Advanced blood screening found Donte's platelet level was low, so a bone marrow aspiration was performed by Rishi R. Lulla, MD, MS, Division Director, Pediatric Hematology/Oncology at Hasbro Children's Hospital. It revealed the devastating news that Donte had acute lymphoblastic leukemia (ALL).

Dr. Lulla explained the diagnosis to the family and presented treatment options, which included participation in a well-established ALL clinical trial. After careful deliberation, the family agreed.

Jennifer Welch, MD, is Donte's hematologist-oncologist. As is protocol for ALL patients, Dr. Welch had an additional diagnostic evaluation conducted after Donte's initial diagnosis. It unearthed more troubling news. "Within two weeks, we discovered Donte had what's called

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—Moya, Donte’s mother

Philadelphia Chromosome positive acute lymphoblastic leukemia (Ph+ALL),” Dr. Welch explains. “This is a rare, aggressive subtype of ALL and can be difficult to treat.”

Targeted agents that specifically combat this genetic mutation would need to be added to Donte’s protocol of standard chemotherapy and administered in rigorous adherence to a complex timing and sequencing schedule. He had an aggressive form of cancer, and his course of treatment would also have to be aggressive to defeat it. The family had a long, difficult road in front of them. But together, they stepped up to meet the challenge. “The first thing we did was move all our stuff into the hospital,” Rich now jokes. “Hasbro Children’s became our second home.”

As fate would have it, Rich knew all too well what Donte would be going through. In 1984, he, as a seven-year-old, was diagnosed with Rhabdomyosarcoma, a rare soft tissue cancer that typically affects children and teens. Rich received successful treatment at the Potter Building on the campus of Rhode Island Hospital under the care of Edwin Forman, MD. A trailblazing pediatric healthcare

provider, Dr. Forman would later become Chief of Pediatric Hematology and Oncology at Hasbro Children’s when it opened its doors in 1994.

Dr. Forman was also an early mentor to Dr. Welch, who says Rich’s experience “has been invaluable as far as informing Moya on aspects of cancer care and showing Donte what life after childhood cancer can look like.” Rich could also relate on an intimate level when Donte had to deal with lumbar punctures, hair loss, nausea, and so many other scary things and setbacks along the way.

These days, Donte is progressing according to plan and will complete his chemotherapy this summer. After that, he will maintain ongoing visits for assessment and medical management purposes and eventually graduate into Hasbro Children’s survivorship program. Reflecting on Donte’s journey, Moya says, “Our son’s diagnosis was pretty much living our worst fear. But having the Hasbro Children’s team by our side was such a blessing. We will forever be grateful for the dedication and care they extended to our family.”

More than that, Donte says his remarkable patient experience has inspired him to pursue a career in pediatric cancer care when he grows up. “I’m going to be a doctor so I can help other kids facing a similar battle,” he says. “And I’m going to work at Hasbro Children’s Hospital—because that place is the best!”

MEET OUR MASCOT, HOPE!



Hope the Harbor Seal was introduced at Hasbro Children’s 30th birthday celebration for staff on February 14.

Hope was created as a single symbol that highlights the unique calling at Hasbro Children’s Hospital, unites diverse teams, and reflects the hospital’s child-friendly spirit. It is a visual reminder that the hard work and specialized knowledge at Hasbro Children’s are all in service of a child-and family-centered approach.

Hasbro Children’s Hospital turns 30!

THREE QUESTIONS WITH FRANCOIS I. LUKS, MD, PHD

*Pediatric Surgeon-in-Chief and Division Chief of Pediatric Surgery
reflects on 30 years of Hasbro Children's Hospital*

How has pediatric surgery at Hasbro Children's changed since it opened in 1994?

We've come a long, long way in 30 years. We've tripled our number of surgical providers, and continued to offer more and newer specialized, complex care . . . allowing patients to stay here in Rhode Island, close to home, for care they once had to travel outside of state to receive.

Hasbro Children's was among the first hospitals to perform fetal surgery—almost 25 years ago—and more recently, became the first in New England to perform in-utero spina bifida surgery. We've also incorporated the most advanced healthcare technologies available. For example, employing Extra Corporeal Membrane Oxygenation, or ECMO, to take over the lung function of our most severely compromised pulmonary patients.

Building expertise in bariatric surgery to treat morbid obesity in qualifying teenagers and developing multidisciplinary programs to comprehensively address a number of diseases, injuries, and congenital abnormalities are also examples of our evolution. Of course, we didn't have the only pediatric emergency department and Level I trauma center in southeastern New England 30 years ago, either!



Francois I. Luks, MD, PhD

What role does the hospital's environment play in delivering patient-and family-centered care and optimizing surgical outcomes?

Environment is enormously important, particularly for a pediatric hospital. Hasbro Children's was progressive in its understanding of this from the start. Conventional wisdom way back was to consider the operating room a sterile temple and you wouldn't dream of letting a patient bring anything personal in there from the outside or even have a parent present. But we knew that creating a friendly, welcoming space can help reduce anxiety, accelerate healing, make pain management easier, and lead to better surgical outcomes. That's why our Child Life Services and art programs are so critical, as are our therapy dogs, allowing kids to drive model cars in the hospital, or have a favorite stuffed animal. Any semblance of normalcy or of home life helps.

Why is philanthropic support so critical to sustaining Hasbro Children's and connecting the hospital to the community it serves?

Without donor support, we simply would not be able to offer many of the programs, services, and amenities that help to make Hasbro Children's the special place it is. And because it's such a special place, that helps us recruit and retain top talent. No doubt, philanthropy dollars directly impact the level of care we are able to provide today and in the future.

WORKING TOGETHER TO IMPROVE HEALTH CARE



Much has changed since Hasbro Children's opened in 1994. What hasn't changed is the commitment to providing the best care possible.

A decade ago, the hospital deepened this promise when it created its Patient and Family Centered Care program.

Built on the premise that no two children are the same and families should be empowered to be a part of the treatment plan process, the program ensures that kids and their loved ones are at the center of every decision made.

"There's been a shift from when you just listened to the doctors to being actively engaged in developing the plan for a child's care – families are the experts on their kids and we want that input," says Erin Scott, MSW, LCSW, Manager of Patient and Family Centered Care.

Seen as a powerful model to improve pediatric health outcomes, Patient and Family Centered Care accounts for families' cultural beliefs, values, and preferences. It fosters respectful, compassionate care that is responsive to the totality of a family's needs, which might include menu and dietary requests, peer support, or feedback on the comfort of a room's sleeper chair.

Rounds have also transformed to include the patient's family and full medical team, allowing a full range of questions to be asked at once and a comprehensive care plan set for the day with everyone's input.

"Open conversations lead to a better experience and to a better understanding of the medicine being prescribed and the tests being ordered," adds Erin. "And when families feel involved in those decisions, it greatly reduces the natural fear and anxiety they already have because their child is hospitalized."

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