



Johns Hopkins All Children's Foundation

Dream Builders

Spring 2019 Newsletter

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Finding Her Niche



Dream Builder Dorothy Dunn just wants everyone to enjoy the things that she and her beloved husband, Frank, a World War II veteran, have appreciated throughout their lives. Raised in Massachusetts, she met Frank at Bridgewater College and they drifted comfortably into a life of education, music, culture and international travel. But quickly in their marriage they recognized that not everyone was as fortunate as they were, and they made a lifelong decision to give back.

Dorothy explains that they started by donating to their own college to help others receive the education that they had. They loved music and after moving to Florida, they enjoyed and began donating to the Florida Orchestra. They immediately recognized that some of their neighbors in the Sun City Center community couldn't afford groceries, so Dorothy joined the Community Foundation of Tampa Bay and helped out. "I didn't want to see anyone going hungry, and this was happening in my own community," she points out.

After losing Frank a few years ago, Dorothy became even more committed to giving and started searching out areas where she thought the money her mother had left her might go to the very best use.

She gifted several annuities for Johns Hopkins All Children's Hospital and immediately began pouring over the literature she started receiving from the hospital.

"I was just so amazed at what was going on there," she says in her typical empathetic fashion. "I just wanted to see those kids getting healthy. Frank and I never had children of our own, so maybe that is what motivated me, but I've found my niche. I just want to make things better for these kids so they can go on to enjoy the type of life that Frank and I enjoyed. There is so much to see and experience and learn out there, and no one should have to miss it. I just want to do more."

As Dorothy got more involved in Johns Hopkins All Children's she met and spoke with several physicians and researchers and recognized the growing opportunity to invest in research, especially pediatric cancer research.

"It is an incredible honor to have someone who believes so deeply in what we are doing at Johns Hopkins All Children's Hospital that they would donate so generously," says pediatric surgeon Nicole M. Chandler, M.D., FACS, FAAP. "As pediatric surgeons, we are tasked to improve the lives of children impacted by cancer, injury, congenital problems and common surgical diseases. Donations we have received have been used to help purchase equipment and resources to expedite and improve the quality of research we are doing to raise the standard of care children receive not only at Johns Hopkins All Children's but across the nation."

As a Dream Builder, a major gift donor, initiator of "The Frank and Dorothy Szafer Dunn Surgical Oncology Research Fund, and Centennial Society member, Dorothy is completely confident that her involvement in the hospital was the right decision for her. "I just want to be a part of what is going on there," she says. "I want to see those kids healing faster and better and that is what research can do for them. The care they are receiving is top-notch and I would feel comfortable recommending the hospital to anyone. I hope my story inspires others to become Dream Builders."

A life well-lived is helping to improve many lives.



Diagnosis Unlocks Answers to Help Patient Walk Again

On a sunny Florida day, Bella walks into an exam room followed by her mom, Megin, brothers Benny and Sammy, little sister Maggie, and her dad, Phil. Their matching T-shirts proudly proclaim they are “Built Duff Tough,” a phrase the North Carolina family coined as a testament to years of juggling complex medical conditions.

For Bella, the key word here is “walk.”

Her story began about two years ago when she started to have random periods of dizziness, ear pain, headaches, neck pain, joint pain and swelling, and hearing and vision troubles. These unexplained symptoms soon began impacting her normal activities. Horseback riding, dance class and her active 11-year-old energy slowed to a halt.

Months later, extreme fatigue and severe dizzy spells led to a drastic turn. Bella unexpectedly began to experience periods of numbness in her arms and legs. That was just the tip of a frightening and mysterious iceberg.

“The scene always plays out in slow motion in my head,” Megin says. “I was on hold with the pediatrician about her dizziness, and I saw her standing wrapped in her blanket. As I got up to help her, she started to fall backward. The back of her head hit the wall, and she fell to the ground.”

Bella was conscious, but her vision was blurred and within minutes her arms and legs were numb. Rushed by ambulance to the local hospital, scans ruled out traumatic injury. With no feeling in her arms, tongue or legs, it was a struggle to

communicate. Though most feeling returned by the next day, her legs did not respond. Bella went home in a wheelchair.

For an energetic kid to suddenly end up with limited mobility was a heartbreaking blow. To keep her spirits up she found creative ways to move about her home. Bella also started dance therapy, horse therapy, aquatic therapy—all activities she loves—and cognitive behavioral therapy to try to retrain her brain to recognize her legs. Though the strength was there and she was mobile with the help of a walker, the feeling in her legs was not returning.

Megin and Phil continued searching for answers as many of Bella’s symptoms continued to become more severe. Despite seeking out specialists and numerous hospital visits, they often found themselves with more questions than answers.

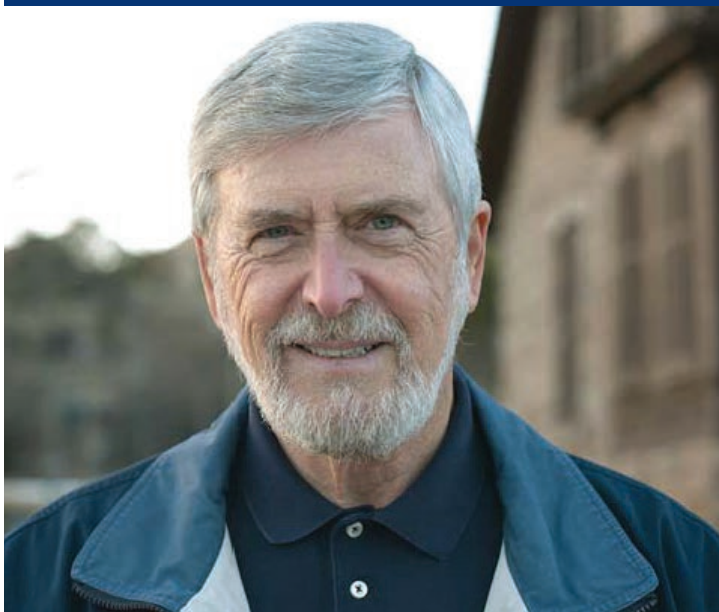
What was causing these strange symptoms? Would Bella ever be back to her active lifestyle?

In It Together

The discussion during a normal family dinner one evening revolved around the topic of “If you could trade lives with anyone, who would it be?” The answer was far from the expected. Benny, third oldest of the siblings at just 9-years-old, voiced without hesitation that he would trade lives with Bella so she wouldn’t have to live with her condition.

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Diagnosis Unlocks Answers to Help Patient Walk Again

Continued from inside

Saying the family is close-knit is an understatement. They are always together, including traveling between the family home in North Carolina and St. Petersburg, Florida, for Bella's treatment. Beyond acting as an integral part of her support system, Benny and Sammy played an unsuspecting role in shaping Bella's path. Both brothers have complex medical conditions and over the past seven years George Jallo, M.D., medical director of the Johns Hopkins All Children's Hospital Institute for Brain Protection Sciences and chief of Pediatric Neurosurgery, has been consulting on their cases.

When there seemed to be no one else to turn to, Megin reached out to the trusted neurosurgeon for advice on Bella's case. This time Jallo offered more than just advice: a team assembled and soon the family was on its way to Johns Hopkins All Children's.

"This is why we travel. We don't really trust anyone else at this point," Megin adds. "He saw a child who couldn't live her life at all and made it a mission to make her well."

For nearly a week, the family made its home on the hospital's neuroscience unit. Bella underwent extensive testing, including a skin biopsy. This test held the answer to her mystery illness: small fiber neuropathy. To finally have an answer was an emotional moment for the whole family.

"We had faced doctor after doctor and specialist after specialist who could not explain to us what was happening to our child," Megin explains.

"Small fiber nerves are the small short nerves of the body that help in managing many automatic functions and also are throughout the skin. A small fiber neuropathy is damage to those nerves," explains Dennis Hart, M.D., senior director of rehabilitation services at Johns Hopkins All Children's Hospital and assistant professor of pediatrics for the Johns Hopkins University School of Medicine, who is overseeing Bella's treatment.

Small fiber neuropathy may either be related to genetics or have no apparent cause. Nerve damage can also come from metabolic issues, infections or autoimmune disorders.

In her case, the cause seems to be an autoimmune issue. The immunoglobulins—or antibody proteins—her body creates don't function in the way that they should and attack her nerves instead of pathogens. To correct this, her treatment involves periodic infusions of intravenous immunoglobulins (IVIG) to replace the ones her body makes. The IVIG treatments will help prevent new nerve damage and allow Bella's body to repair itself.

One Step at a Time

Like all journeys in life, there have been ups and downs. Bella's treatment is not always easy. Every two weeks she receives the IVIG therapy at home via a subcutaneous infusion involving four to six needles in her abdomen. This is expected to last for at least a year with follow-up trips to Florida every two to three months. With this treatment, side effects are less intense and she can make it between treatments with no relapse.

While Bella has started on a road to recovery, there is still much to learn about small fiber neuropathy in children and how to most effectively treat it.

"These issues seem to be on the rise in the pediatric and adolescent population; however, there is very little literature to date," Hart adds. "I'm in the process of gathering a cohort of patients with the goal of researching this condition."

Bella and her family remain hopeful for the future.

After one round of treatment, Megin recounts a family trip to a museum. Bella would normally struggle to walk, but this time she was keeping up with family and even had enough energy to take on a rock wall. She is riding a bike again after nearly a year of being unable to and even danced down the local Christmas parade's 2-mile route with her dance studio.

"We spent so much time watching her down in the bed all the time, in and out of the hospital, living in a wheelchair, and having doctors just kind of throw their hands up," Megin says. "Now we are getting our daughter back."



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