

Meet Norah

Norah is a 11-year-old who is a rising sixth grader at Diamond Middle School. She loves her friends, fashion, art, reading and her three sisters.



When Norah was 7, her parents noticed that she was limping a bit. What they thought would be a quick trip to the doctor to have her leg checked turned into an ambulance ride to Boston Children's Hospital where they discovered that Norah had a mass in her brain the size of a tennis ball. Norah underwent immediate brain surgery to remove the

mass, but due to its location, only 80% could be removed as the remainder was entwined in her motor cortex. The doctors determined the mass to be the most aggressive type of brain cancer, Glioblastoma Multiforme (GBM), which historically has a very low survival rate. At this point, Norah's parents were given two choices – do nothing and Norah would succumb to the tumor, or resect the remaining tumor and Norah would likely lose motor functioning on the left side of her body. Due to this risk and overall bleak prognosis, every doctor recommended they do nothing.

Nevertheless, Norah's parents opted to proceed with the second brain surgery to remove the remaining tumor and at the same time. **Norah became the sixth child in the world to try an experimental phase 1 trial** of an immunotherapy injection at the site of the tumor. Miraculously she emerged from surgery with a successful resection and the ability to move all parts of her body! Since recurrence of the tumor is likely imminent, Dana-Farber has Norah on an aggressive follow up treatment plan that began with 33 treatments of radiation to the brain, weekly chemotherapy, multiple surgeries to place a port and g-tube, stem cell collection, platelet transfusions, red blood cell transfusions, and more. While this process has been grueling for Norah and her family, her most recent 3 ½ -year MRI shows no evidence of disease!

Norah's parents truly believe if it were not for the incredible doctors at Dana-Farber, who are the leaders in the world with cancer research and treatment, Norah would not be with us today. Money raised at events such as the Lexington PMC Kids Ride goes to Dana-Farber to fund cancer research.

Meet Hugh

Hugh is a 10-year-old who is a rising fifth grader at Estabrook Elementary School. Upon moving from Australia to Lexington in 2013, his parents described him as a happy, energetic and vivacious young boy who was full of life and always had something to say.

In January 2015, after being unwell with "viral like" symptoms and a headache that progressively got worse, Hugh was diagnosed with Acute Lymphoblastic Leukemia (ALL). He was immediately admitted to Boston Children's Hospital for the first phase of his treatment, a 32-day intensive chemotherapy called "Induction Therapy". This therapy proved to be incredibly challenging as Hugh lost all of his strength and energy to talk and walk. Furthermore, fever and high blood pressure kept Hugh in the hospital for much longer than anticipated - he was an inpatient for 10 weeks.

For the next 2-year phase of his treatment Hugh moved back home, attended school and received weekly chemotherapy at the Jimmy Fund Clinic. **Here, Hugh and other patients were the direct beneficiaries of PMC dollars at work** as the nurses and clinic volunteers created an unbelievably uplifting, supportive and fun environment where their sick patients can still feel like kids by offering them arts and crafts, games, books, video games, music, movie and popcorn days, Dr. Seuss week and so many other great events. Their goal was to take Hugh's mind off the pain and boredom that can be associated with these visits and make him feel special, therefore aiding in his recovery.



Hugh is getting back to his active life now that his treatments are complete and his energy is returning. He loves playing baseball, using the pitch-back in his backyard and going to Red Sox games. He also loves skiing and riding his bike. He looks forward to riding with his sister and other Lexington PMC Kids Ride riders on September 15th.