

# Beating Pediatric Leukemia

After being diagnosed with acute lymphoblastic leukemia, 7 year-old Ryan was officially declared in remission in April 2019.

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When Anthony and Lauren Terebetsky took their 7-year-old son, Ryan, to the hospital for blood tests, they were thinking about dinner, Ryan’s homework, their daughter starting spring softball, his job at the firehouse and hers as a teacher—not a life changing diagnosis. “Three hours later, the doctor and nurses asked us to come into another room to talk about the test results. Nothing good comes from leaving the patient to talk,” said Mr. Terebetsky. He and his wife heard the words no parent ever expects to hear. Ryan’s blood tests were positive for Acute Lymphoblastic Leukemia (ALL), the most common type of cancer in children. “After I heard leukemia, I shut down. I don’t remember anything for the next 10 minutes,” he said. Leukemia is caused by the bone marrow producing abnormal white blood cells that grow out of control. Eventually, the leukemia cells outnumber healthy blood cells and the blood cannot perform essential functions such as preventing infections, carrying oxygen, and clotting.

In the months leading up to this fateful day, Ryan had lost a few pounds, was tired all the time, and had strep throat twice. At first their pediatrician prescribed a low-dose iron supplement for anemia. The treatment helped initially, but their worry increased when they noticed Ryan’s heart beating unusually fast after playing with his sister. “I could actually see his heart throbbing under his skin when I lifted his shirt. It was an incredibly scary sight,” said Mrs. Terebetsky. “We knew something wasn’t right, so we took him back to the pediatrician, who suggested we go to the hospital for a full exam and blood tests.”

Once diagnosed, Ryan was admitted to the Hematology Oncology Unit at Bristol-Myers Squibb Children’s Hospital, in New Brunswick, New Jersey, and started treatment the same day. They met Former Damon Runyon Clinical Investigator Peter D. Cole, MD, who would become Ryan’s primary doctor soon after. He explained that Ryan would remain in the hospital for a month of intensive chemotherapy treatments, multiple blood and platelet transfusions, along with many oral medications. After this, he would continue with a lower-dose chemotherapy and follow-up care every three weeks for two years. With this treatment regimen, nearly 100 percent of patients go into remission, which was not the case 50 years ago.

## Preventing “Chemo Brain”

Dr. Cole enrolled Ryan in a clinical trial for children with leukemia that aims to reduce the toxicity of treatment. “Most kids with leukemia are cured with chemotherapy, but I am trying to prevent

the accompanying cognitive decline that may become permanent,” he said. During treatment, patients may experience changes in brain function, often called “chemo brain.” Children may be particularly susceptible to this damaging side effect of cancer therapy because their brains continue to grow and develop until young adulthood.

Dr. Cole is leading a project to reduce the impact of chemo brain, which is grounded in work that grew out of his Damon Runyon Award in 2003. Dr. Cole previously uncovered that chemotherapy causes receptors in the brain to be overstimulated, which impairs new memory formation. “For the first time, this trial is testing cognitive skills to identify the earliest stage during treatment when we see changes in memory and attention,” explained Dr. Cole. He is also investigating drugs that bind to the receptors in the brain affected by chemotherapy. This may be able to block the damage of the treatment and prevent the effects of chemo brain. Now, a little over a year into treatment, Ryan is doing well. “He went into remission right away and hasn’t had terrible side effects,” said Dr. Cole. “Ryan is a really bright kid who’s fun to take care of. Every time I see him in clinic, he’s watching some educational video, or learning from his big facts book about physics or religions of the world—always something different. I want to make sure this doesn’t change because of cancer.”

## **#RyanStrong**

Ryan had to spend Mother’s Day and Memorial Day weekend in the hospital, and missed the last month of school, but he never complained. “This is what we do. He is matter-of-fact about it,” said his mother. Ryan was officially declared in remission in April 2019 and finally cleared to go home. Ryan will continue to receive chemotherapy treatments every three weeks until April 2021. Through all the challenges he has faced, Ryan continues to have a positive outlook and a smile on his face. He loves playing on his Little League baseball team and cheering on his 14-year-old sister, Abigail. Ryan’s family and friends wear wristbands that read #RyanStrong and “One Tough Kid,” sayings he has lived up to. Dr. Cole is optimistic that cancer research will continue to save more patient lives with fewer side effects. “Without Damon Runyon funding early in my career, I would not have been able to continue laboratory research in a meaningful way. The clinical trial Ryan participated in and others I am conducting are direct offshoots of that,” he said. “My work builds on the research that came before me and will benefit the next generation of kids.”

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