A majority of children with acute lymphoblastic leukemia are cured. But for the rest, the treatment journey can be long and uncertain.
Avery Lachapelle is 11 years old. He is an average student, he hangs out with his cousins, he enjoys playing video games, and he hasn’t yet decided what he wants to be when he grows up. His mother, Trish Daly, describes him as an amazingly resilient child. The truth of that description becomes apparent upon learning that Avery was diagnosed with leukemia at the age of 14 months and has been in and out of hospitals to combat its recurrence ever since. “Our family doctor knew right away,” Trish said of the initial diagnosis. “They sent us for blood work on a Thursday; Friday was the bone marrow biopsy. Saturday, they started chemo.” Although the idea of cancer was terrifying, Trish will never forget the doctor saying, “Oh, it’s not as bad as you think.” Acute lymphoblastic leukemia (ALL) is considered the good cancer. And in fact, ALL is routinely trotted out as a success story in the war on cancer—a disease that was nearly universally fatal in the 1960s now has a cure rate of over 80 percent. But for those children who are not in that fortunate majority, the future is much less bright.

“He had two years of standard chemotherapy after the diagnosis,” recalled Trish, “and then relapsed a year later.” After the relapse, Avery had a bone marrow transplant in March 2004. “The doctors were shocked when it came back in November 2007,” added Trish, explaining that there is only a five percent chance that ALL will recur two years after a transplant. Since then, Avery has had a second (blood stem cell) transplant and an experimental therapy (rituximab). “That’s the thing about Avery,” said his mother. “He always responds to therapy, but for some reason, the cancer keeps coming back.” When the cancer again showed signs of recurrence in February 2010, his doctors in Canada had reached the limit of their therapeutic options. “Our doctors are wonderful at home,” said Trish, “They did some research and found out about this place.” Avery was the ninth child enrolled in a clinical trial run by Alan Wayne, M.D., at the NIH Clinical Center to test a second-generation investigational immunotoxin (HA22 or moxetumomab pasudotox) developed by Ira Pastan, M.D., Chief of CCR’s Laboratory of Molecular Biology. “It did wonders for him,” said Trish. But once again the cancer showed signs of returning, so his NCI care team decided to enroll Avery in a new trial of a cancer vaccine approach to ALL that Dr. Wayne and colleagues have developed at the NIH. Avery’s mother is not thinking about the long-term prognosis. “I just do one day at a time,” she said “Today is a good day, let’s focus on that.”

Trish stressed that despite the years devoted to Avery’s cancer and the unexpected life changes it has wrought, she considers herself and her son lucky that “all these new therapies are available.” She thanks the Canadian healthcare system and places like the NIH Clinical Center. “I am forever grateful that we live in a world where this kind of research is possible.”