A longtime survivor helps sick children find a voice.

As a talented high jumper in middle school, Kelly Cotter, of Madison, Wis., had yet to face her biggest hurdle. At the age of 11, the usually lively, athletic pre-teen became tired to the point of not being able to climb stairs. She developed swollen lymph nodes in her throat, a rash on her legs, and bone pain. Her mother took her to the doctor, thinking her daughter might have mononucleosis. The diagnosis was far more devastating.

Kelly had childhood acute lymphoblastic leukemia (ALL). Leukemia is a cancer that involves the blood-forming tissue of the bone marrow, spleen, and lymph nodes. The bone marrow controls the production of all the body’s blood cells—red and white blood cells and platelets. But with leukemia, the marrow produces large numbers of abnormal, immature white blood cells (lymphoblasts), which crowd out healthy red and white blood cells and platelets. Childhood ALL is the most common form of leukemia in children and one of the most common childhood cancers.

When Kelly was diagnosed in 1988, the chances of being cured of ALL were promising but not great—about 75%. She underwent the rigors of chemotherapy and radiation in the spring of that year. Despite the treatment, her body was resistant to the drugs and she suffered a relapse by summer. With this relapse, her chance of a cure dropped dramatically, to just 25%.

A bone marrow transplant (BMT) was Kelly’s only hope. With the BMT Kelly had, high doses of chemotherapy and radiation are used to destroy leukemic cells. Since this process severely damages the bone marrow’s ability to produce blood cells, healthy bone marrow cells must be given intravenously from a compatible donor. This stimulates new bone marrow growth. Fortunately, Kelly’s brother Adam, then 8, was a match.

A young trouper becomes an activist

Before the transplant, the chemotherapy and radiation ripped
Kelly and her brother, Adam

Unable to talk because her mouth was so sore, she wrote ideas on a notepad for a fundraiser to benefit the Leukemia & Lymphoma Society. The event, a school dance called the Stomp-a-thon, ultimately raised $20,000.

A voice for kids with cancer

In 1993, Kelly got involved in a hospital event called Kids with Courage, a five-year reunion for childhood cancer survivors. With her mother, she put together Kids with Courage, a book of survivors’ stories that’s still circulated at many children’s hospitals.

A decade later she earned a law degree. But while in college, she also started a website called Outlook (www.outlook-life.org), filled with FAQs on childhood cancer. It also includes a host of resources such as books, camps, organizations, and more.

By 2003, Kelly had become the director of legislative affairs for the CureSearch National Childhood Cancer Foundation in Bethesda, Md. While there, she was a driving force behind the Conquer Childhood Cancer Act. To get the bill passed, she met with Congress members and helped organize an annual event called Reach the Day, which brought families touched by childhood cancer and health professionals together. At this event, she helped the families set up meetings with their congressional representatives. The result: The bill was signed last year; it grants $150 million over the next five years for research.

It is research and clinical trials, after all, that have dramatically increased the survival rate among children with cancer. Forty to 50 years ago, the survival odds were only 10%; now almost 80% of children achieve long-term survival.

That kind of statistic keeps Kelly going. In 2004, she married scientist Bill Pappano. They live in Libertyville, Ill., and are in the process of adopting a child. She now works to procure grants for the United Way, and continues her activism for childhood cancer as a member of an advisory board for the National Cancer Institute. It’s heartfelt work for Kelly—a mission, in fact. “Children don’t have a vote,” she says. “It’s important to mobilize the community to speak for those who can’t speak for themselves.”

—Ann Ferrar