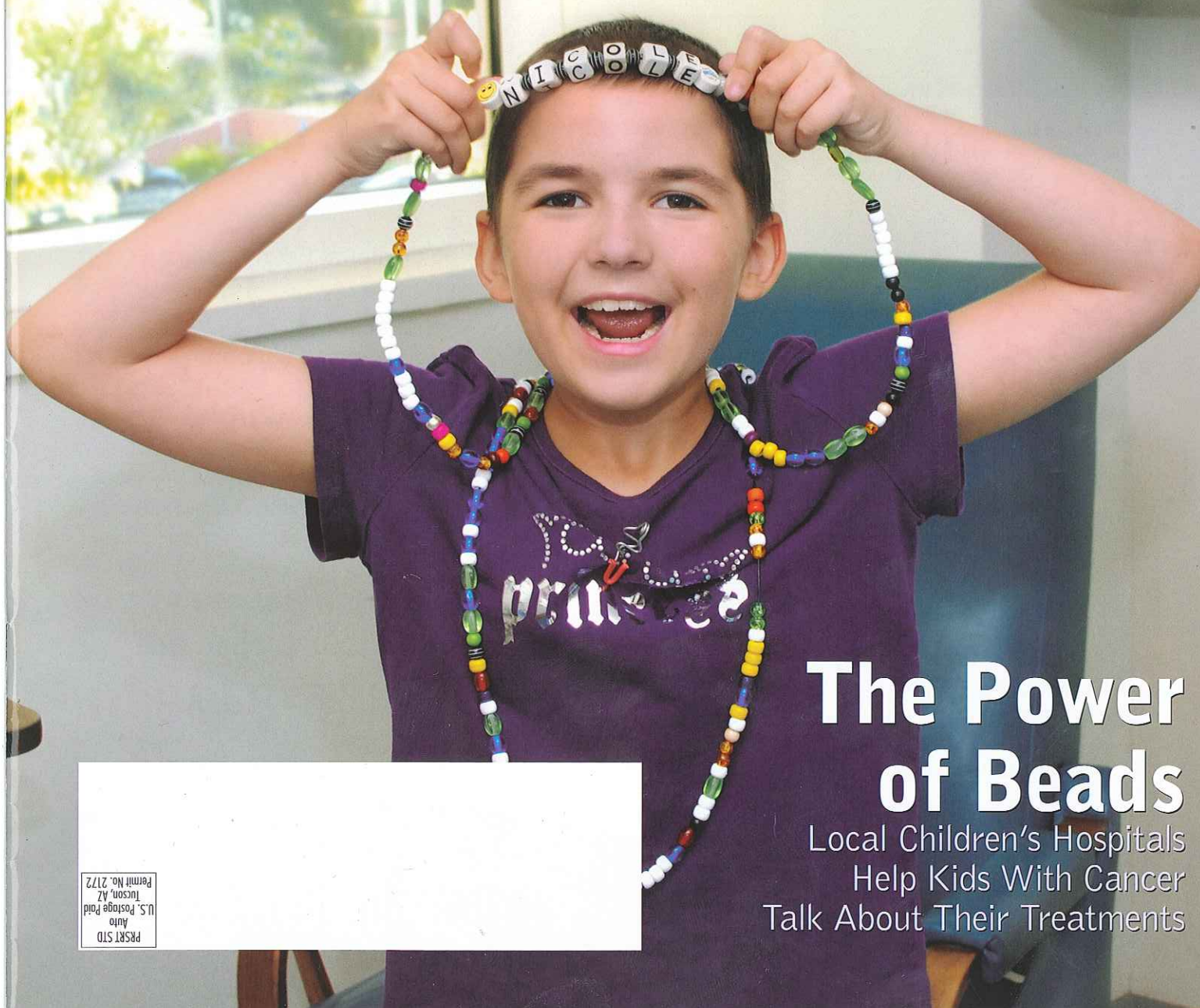


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## The Power of Beads

Local Children's Hospitals Help Kids With Cancer Talk About Their Treatments

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# The Power of Beads

## Local Children's Hospitals Help Kids With Cancer Talk About Their Treatments

By Carina Daniels

In a hospital bed decorated with Disney princess pillows, Alyssa Justice, 5, picks out colorful beads with social worker Tracy Jones, M.S.W. Tracy is helping Alyssa pick out what she calls a "tomato juice bead," the red bead she earned for her most recent blood transfusion. Alyssa and Tracy will attach "tomato juice" to one of the long strands of colorful beads that represent each procedure and treatment Alyssa has bravely completed as a leukemia patient at Children's Hospital & Research Center Oakland.

Alyssa and other children with cancer endure countless probes, injections and tests. "They are brave and work hard to get through their treatments. They should get medals, and that's one of the reasons why we honor Alyssa and our other oncology patients with Beads of Courage," says Tracy, one of Alyssa's favorite caregivers and

closest friends at Children's Hospital & Research Center Oakland. Alyssa's name for Tracy is "the Bead Princess."

Children's Hospital & Research Center Oakland adopted Beads of Courage in 2005, and was the first large hospital in the country and the third overall to adopt the program. The children who participate in the Beads of Courage program receive a string of beads that spells out their first name and then receive colorful beads, each representing a different treatment milestone. There is a red bead to represent blood transfusions, a white bead for each week of chemotherapy, a brown bead for hair loss and glow in the dark beads for radiation treatments. There are also special glass beads known as courage beads. A child receives a courage bead after they do something particularly courageous or overcome a fear. Children receive a purple heart bead at the end of their treatment.

Jean Baruch, a pediatric cancer nurse, founded the nonprofit Beads of Courage program in 2004 at Phoenix Children's Hospital. As a clinical nurse, she wanted to give children a gift when she was at their bedside administering an IV or assisting with a procedure. She decided to give her patients beads not only because they are small and portable, but also because throughout history and cross culturally, beads have been used to represent honor and accomplishment.

"In my research, I found that these beads can help address the emotional needs of children at their bedside. They also help patients communicate better with their caregivers and with other patients. We use these beads as a tool to improve and elevate our standard of care," explains Jean.

Oncology nurse Philippa Doyle, R.N., brought Beads of Courage to Children's Hospital & Research Center Oakland after she heard Jean talk about the program at a pediatric oncology nurse conference. Philippa was one of the first nurses to help Jean keep track of how Beads of Courage benefits children, caregivers and families.

"My early partnership with Philippa and the other staff at Children's Hospital Oakland helped me show that this program can make a big difference for kids and families who are fighting cancer. Children's Hospital Oakland helped pave the way for the implementation of the Beads of Courage program at other Children's Hospitals, and I've been very thankful for their support." There are now 50 children's hospitals in 25 different states that are giving their

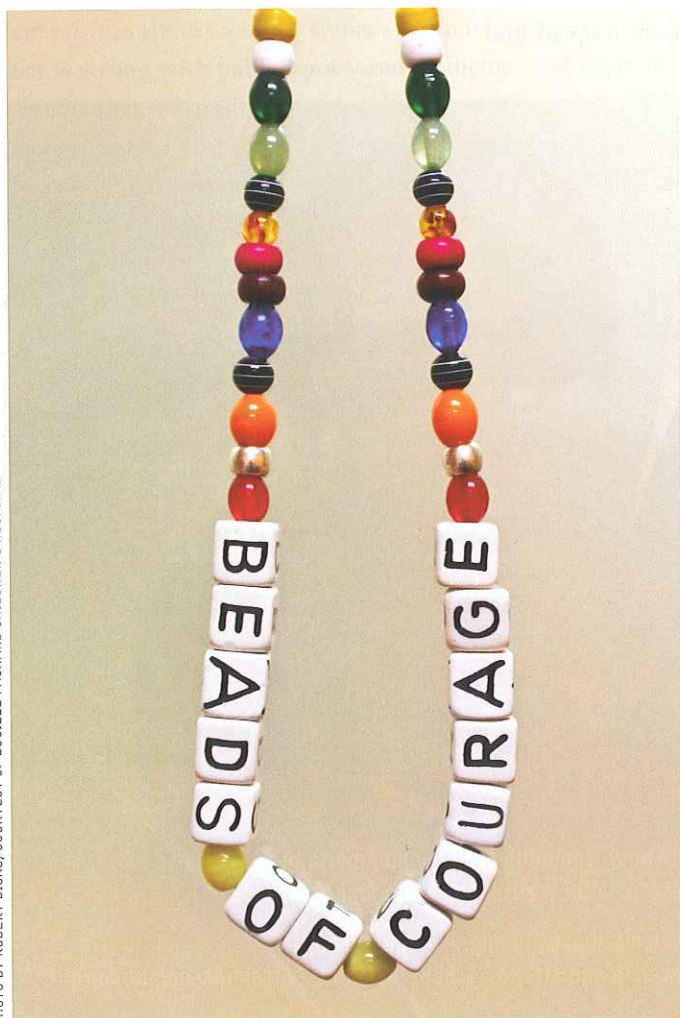


PHOTO BY ROBERT DICKS; COURTESY OF LUCILLE PACKARD CHILDREN'S HOSPITAL

patients Beads of Courage, including Lucille Packard Children's Hospital at Stanford. Kaiser Permanente Oakland has also joined the program.

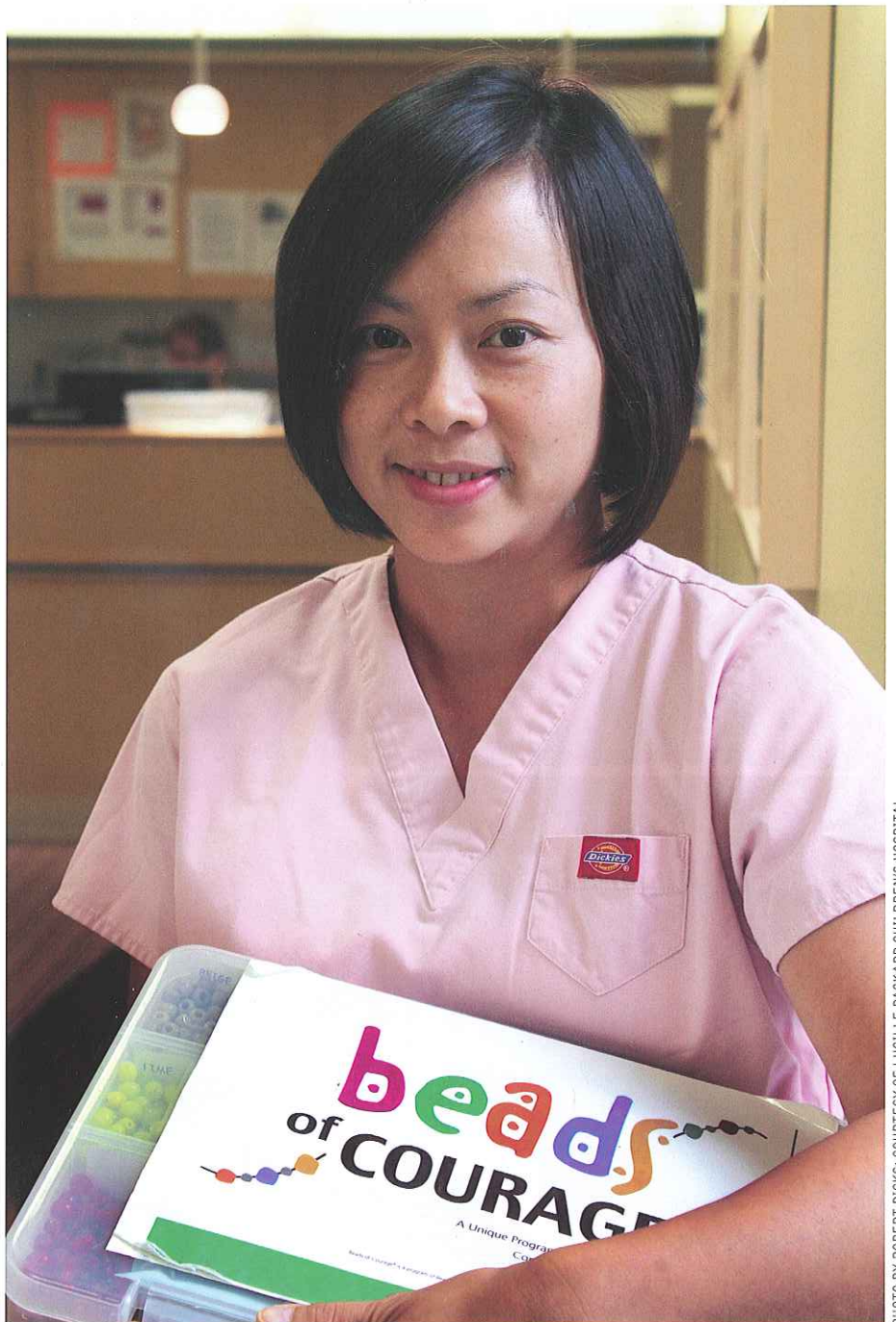
"It is amazing how much the beads help her understand," says Alyssa's mother, Jamie. "She can tell you what some of the beads mean and she and Tracy make up playful names for them." The nurses and social workers turn the beads into a fun historical document of therapy by making up games with the children when they pick out their beads.

"When I come into Alyssa's room to give her beads, right away she will say something like, 'Tracy, I need a milk bead — I had chemo this week.' The chemo beads are white, which is why she calls them 'milk beads,'" explains Tracy. "Because of the beads, Alyssa and I are able to overcome the seriousness of her treatments by talking openly and playfully about her beads; they are great therapeutic tools!"

Jamie also appreciates the beads because they make it easier for family members to ask questions about Alyssa's treatments. "When Alyssa's grandparents, cousins and our friends come into her room, they want to know what the beads are for and what they represent. The beads are a great conversation starter. Our friends and family use the beads to guide the questions they ask us and Alyssa about her treatments — no one stands there not knowing what questions to ask."

Jamie's dad provides a great example of how the beads can help bring family members closer to a loved one who is fighting cancer. "The beads have really helped Alyssa talk to my dad about her treatments. He gets really enthusiastic about the beads. So, now, whenever he comes to visit, Alyssa says, 'Oh, Grandpa! Look how many beads I have now!' And she'll always show him how many more beads she has gotten since his last visit. When Alyssa talks about her treatments by referring to the beads, our family and friends begin to realize how much Oakland is doing for Alyssa. We all appreciate what Children's is doing to help Alyssa stay positive and brave during her treatments."

Diep Luong, R.N., who oversees the Beads of Courage program at Lucille Packard Children's Hospital, agrees that the beads have an amazing effect on how children view their treatments.



Diep Luong, R.N., of Lucille Packard Children's Hospital at Stanford

PHOTO BY ROBERT DICKS; COURTESY OF LUCILLE PACKARD CHILDREN'S HOSPITAL

"Some kids look forward to treatment because they get the beads," says Diep, adding that the glow in the dark radiation beads are the most popular. Many young patients will come to her first thing to report on what beads they are owed. Diep also points out that the beads create a history of treatments for patients and their parents.

In addition to helping young patients understand and keep track of their treatments and procedures, Beads of Courage can also be used as a tool for older children to help them reintegrate back into school. "Another reason why I wanted to bring the program to Oakland was that I realized sometimes children have a hard time going back to school and talking to their classmates about their experiences in



Alyssa Justice with her mother, Jamie Simons-Justice, and Tracy Jones, M.S.W.



PHOTOS BY ERIN GOLDSMITH; COURTESY OF CHILDREN'S HOSPITAL & RESEARCH CENTER OAKLAND

the hospital. I thought that the beads could help them share their stories with their schoolmates," says Philippa.

Noah Vieira, 10, has a 10-foot-long strand of Beads of Courage. He was diagnosed with brain cancer when he was in the first grade, and he missed second grade for his original treatments. When he came back to school for the third grade, he and Children's Hospital & Research Center Oakland psychologist Dina Hankin, Ph.D., brought Noah's beads to school to help him talk about his experience at Children's Hospital & Research Center Oakland in front of his classmates.

"I wasn't nervous. The beads helped me tell my story. I always start at the beginning, with my first bead," says Noah, who just got back from a family ski trip with his parents in Lake Tahoe.

Larry and Nancy, Noah's parents, explain that not only did the beads help Noah talk about his treatments to his classmates, they also helped his school friends understand what Noah was referring to. "The beads helped Noah's story be more tangible for the kids. Noah would say, 'every black bead is a poke.' Most third graders don't understand what chemo is or how big a deal surgery is, but they all know what a poke feels like, because they've had to have shots."

Noah's younger brother, Evan, also gets his own Beads of Courage. He participates in the SuperSibs program. This is a program that Jean started to reward and acknowledge siblings of cancer patients, who at times may feel left out. Philippa brought the program to Children's Hospital & Research Center Oakland because she noticed that sometimes siblings feel guilty that their brother or sister got sick instead of them.

"Evan loves his SuperSibs beads," Larry says. "They encourage him to be a better sib. They also help him learn about medicine. He even knows what a stem cell transplant is now!"

Larry and Nancy believe that the beads can be therapeutic for parents, too. "When Larry and I string the beads for Noah, we are able to reflect on everything that our son has accomplished as a young, brave cancer patient. When we sit and bead and talk about his treatments, we express how proud we are of our son!"

Jamie explains that even after Alyssa receives her purple heart bead for completing her cancer treatments, Beads of Courage will still be a part of their lives. "Alyssa wants to make a Beads of Courage curtain from all the beads she has earned. She also wants me, her father, and two brothers to have our own beaded necklaces. These necklaces will be a constant reminder of the amazing care and support we received from Tracy and our other friends and caregivers at Children's Hospital Oakland."

*Special thank you to Children's Hospital & Research Center Oakland for contributing this article. ■*