

Hope and a heart transplant

Staying in the hospital can be a stressful experience, especially for a child. Children's Hospital of Wisconsin has a program that helps ease some of the stress related to a stay or visit to the hospital.

Kohl's Child Life Program helps prepare children for a stay in the hospital and provides distraction during procedures. The program plays an important part of the healing process. Child Life specialists use a number of techniques to help children deal with hospital stays or medical procedures.

- Playing together helps children express themselves and can act as a stress reliever.
- Group activities such as art and crafts or games help children remain social and engaged with their peers and can help relieve some of the stress of being in a hospital.
- Preparation and support helps patients better understand medical procedures. Pictures, books and realistic medical equipment are used to help explain to a child what they will experience before, during and after their procedure. Child Life specialists also are available to provide support, distraction and relaxation techniques during the procedure itself.

One unique offering of the Kohl's Child Life program is the expressive arts program.

It was through art that one 5-year-old patient, who was waiting for a heart transplant, was able to express herself and learn to cope with her illness. On May 12, 2009, Faith was flown to Children's Hospital's Herma Heart Center from her home in Michigan. Days waiting for a heart turned into weeks with no good news. She was interacting with staff and family less. She smiled less. She was tired of being attached to a machine and really disliked it when staff came in to

(over)



*Art therapist Marianne Huebner
and heart transplant patient Faith*



2009 Child Life program highlights

- Child Life visits are provided free of charge to patient families.
- In 2009, 120 young children throughout Wisconsin benefited from Child Life school visits preparing students for the return of a Children's Hospital patient back into the classroom setting.
- Ten Milwaukee-area community schools participated in the coordinated efforts of the Art Therapy program, displaying young artists' work in the hospital setting. Similarly, a patient perspective art display represents patients' artistic expression of their hospital experience.
- Saturday-morning hospital tours provided 371 patients and their siblings who were scheduled for surgery with an opportunity to learn about the hospital environment and prepare them for their hospital stay.
- Infant massage classes are offered to families with new babies to teach parents the importance of touch and massage for calming and bonding with baby.
 - Child Life staff assist in preparing young siblings for a visit to see their brothers or sisters in the Neonatal Intensive Care Unit.

check her temperature and blood pressure, give her medicine and examine her. Staff saw that Faith needed something that would help her cope with the unknown.

Marianne Huebner, art therapist, began working with Faith. They got to know each other by playing – and making a mess. During those play sessions, Huebner assessed Faith's emotional state. This helped Huebner develop a treatment plan.

"The creative process offers self-expression, emotional release and helps create a sense of play or fun, helping children decrease the effects of stress or anxiety," said Huebner. "It is during the first several art-making times together that I can begin to use the art process to guide the patient toward a place of understanding and healing. I saw Faith every day and it was shortly after we began to work together that she began to display what she could not put in words but what she was really feeling."

One day, Huebner asked Faith and her sisters to try something new. She brought out modeling dough, and some markers. One sister made a container and colored it with words of love. Faith made a heart. Faith's mom, Toni, and her sisters also made hearts. One by one, Faith asked for each heart, colored each heart black, crumpled them up and threw them on the floor – beginning with the one she made. Faith was frustrated and feeling hopeless. This art session allowed the family to talk about the frustrations of waiting for a heart.

As weeks turned into months, two hearts were matched to other patients. Faith feared another heart wouldn't come and that if it did, it would be given to someone else. Faith questioned if the heart that was meant for her would know where to come when it got to the hospital.

Huebner and Faith's mother suggested that Faith make a sign for the heart so it would know where to go when it got to the hospital. The sign, a large picture of a heart, became the symbol of her hope, faith and determination. Faith began to paint hearts every day, cutting them out, and giving each heart a set of wings to fly.

The project evolved to include all of Faith's care staff and visitors. Everyone who visited was asked to paint their hands and press them on paper. Faith became more than just a patient and established herself firmly in a community of care. Faith would cut out each set of handprints and paste them to a cut-out heart. The handprints were wings. Each winged heart became a message of hope to Faith, her family and the staff. The wings were placed all around her room. It was when the chain of winged hearts completely encircled Faith's room that a real heart was located. She had a successful heart transplant July 25, 2009. On Aug. 12, 2009, Faith and her family returned to their home in Michigan.

How you can help



Children often are impacted by local, state or federal policies that affect their health care. They need others to be their voice, which is why these efforts rely on the strength and action of people who want to make a difference for children.

Join Children's Hospital of Wisconsin's Children's Advocacy Network today and help us make a difference in the lives of children and families in our communities. Through CAN, you help ensure that children's concerns are heard when policies are being made. The network sends members action alerts and legislation updates and provides tools that you need to help you take action on issues important to children's health.



Join CAN at chw.org/can.