Amy Wynia was born with serious heart problems. Now a healthy adult, she's part of a group of adults with reconstructed hearts who still need care. Children's of Minnesota is preparing to care for this new generation.

neort

By GINGER BUXA PLUMBO

Amy Wynia, 5, returns home with a T-shirt from Minneapo-

lis Children's Medical Center

for heart surgery.

Photos courtesy of Amy Wynia

2

shortly after her hospital stay

Photos by Brady Willette

ust a few decades ago, babies born with congenital heart disease rarely survived beyond infancy or early childhood. If they did reach adulthood, it was nothing short of amazing.

Amy Wynia was one of those amazing babies. Immediately after her birth in 1973, and again at ages 5 and 15, she endured surgery on her heart. The last two surgeries took place at Minneapolis Children's Medical Center, which is now the Minneapolis campus of Children's Hospitals and Clinics of Minnesota.

Now a healthy, active adult, Wynia represents a new generation from a medical standpoint. She's among a growing group of adults who were born with heart defects, received treatment as children, and now need specialized care for their reconstructed hearts.

Children's of Minnesota is developing a program of care for these adults, who still need the expertise of pediatric cardiologists and surgeons familiar with their heart defects. (See article on page 4.)

A blue baby who needed surgery

Wynia was born with a heart defect called Tetralogy of Fallot. It's among the conditions sometimes called "blue baby" syndrome because the infant's skin looks blue from a lack of oxygen in the blood.

Tetralogy of Fallot combines four abnormalities: a ventricular septal defect (a hole between the ventricles); pulmonic stenosis (a narrowing of the valve leading to the pulmonary arteries); the position of the aorta (the major

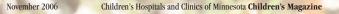
Directing Amy's care at Children's for a number of years was her pediatric cardiologist, Blanton Bessinger, MD. She named her teddy bear after him. artery from the heart to the rest of the body) over the ventricular septal defect; and the presence of thickened muscle tissue in the right ventricle, making the heart work harder to pump.

Wynia's first surgery took place at the University of Minnesota Hospital when she was less than 24 hours old. The cardiac surgeon created a connection between the aorta and the artery to the lung, providing more blood flow. This improved her color. Wynia's physicians knew that she would need more surgeries later on. As she grew, so too, would the strain on her heart.

By the time she was 5, Wynia's heart needed a more complete repair. Surgeons at Children's closed the hole between the two lower chambers of her heart. They also removed the muscle obstructing blood flow to the lungs, opened up the pulmonary valve, and closed the surgical connection of the lung artery and aorta created when Amy was a newborn.

Wynia spent several weeks in the hospital. "That hospital stay changed my life in so many ways," she says.

She recalls her mother's elation at how much more energy and spunk she had. "I remember my mom saying I was a



totally different kid because for the first time, I could keep up with the other kids. As a result, I became more outgoing and more active," Wynia recalls. And for the first time, her skin color became pink.

The seeds of her child life career, sown at age 5

Although she didn't realize it for years, that hospitalization played a significant part in her career choice. At Children's Wynia met a young child life specialist named Sheila Palm, who she called "Sheila the play lady."

Because Wynia's condition required regular check-ups and periodic procedures to monitor her heart function, she became a "frequent flyer" in the hospital and clinics. She and her family kept in touch with Palm. When Wynia began exploring careers as a young adult, she met with Palm and asked a simple question: "What does it take to become a child life specialist?"

Acting on Palm's advice, Wynia received a degree in psychology and family studies from St. Olaf College in Northfield and did her internship at Children's. She is now in her 10th year as a child life specialist at Children's. Wynia credits her experiences as a patient and her positive memories of dedicated health professionals at Children's as inspirations for her career choice.

For most of those early years, Amy's pediatric cardiologist was Blanton Bessinger, MD. She fondly recalls his booming voice, gentle nature, and how she would sit in Bessinger's chair during her clinic visits.

"I loved him so much that when I was 5, I named my teddy bear Dr.



Bessinger," Wynia recalls. Later, Bessinger attended her high school graduation and her wedding. "He got to know me and my family. Dr. Bessinger went beyond just caring for my body. He cared for me personally."

By age 15, Wynia's heart had again outgrown the previous repairs. Her surgeon at Children's placed a valve to stop the backflow of blood from her lungs. Amy leads an active life with her children, Ben and Grace. She continues to receive specialized care for her congenital heart condition from a pediatric cardiologist.

During a visit to Children's, Amy works on a medical play activity with Sheila Palm, child life specialist. Palm now directs Children's child life department.

Helping adults with congenital heart disease: a new program at Children's

Children's Hospitals and Clinics of Minnesota offers one of the largest and most comprehensive programs in the region for children with heart problems. Cardiovascular care is one of the leading programs at Children's, called a cornerstone program. These are major programs meeting rigorous criteria for excellence, including clinical research, use of advanced technology, and evidence-based practice.

Now, Children's is extending its expertise to offer a comprehensive program to better care for adults with congenital heart disease.

Approximately 1 in 120 infants has a heart defect at birth, called a congenital heart problem. Thanks to surgical and medical breakthroughs, 90 percent of children born with heart defects are now expected to live to adulthood and beyond. At Children's of Minnesota, the number of adults receiving care for congenital heart disease has grown about 10 percent each year for the past five years.

"Children's has one of the largest pediatric cardiovascular programs in the Upper Midwest," says David Overman, MD, a pediatric cardiac surgeon at the Children's Heart Clinic. "We are in a position to develop the first center in the Twin Cities area for adults with congenital heart disease and to do it well."



Pediatric cardiologist Kirsten Dummer, MD, specializes in treating adults with congenital heart disease.

To respond to this need, Children's and the Children's Heart Clinic collaborated to recruit Kirsten Dummer, MD, a pediatric cardiologist who specializes in adult congenital heart disease. She is among only a handful of U.S. physicians with this specialty in cardiology. Dummer began her service at Children's and the Children's Heart Clinic on Nov. 1.

Dummer received her medical degree from the University of Arizona Health Sciences Center.

She completed a pediatric residency at Denver Children's Hospital/University of Colorado and a fellowship in pediatric cardiology at Children's Hospital Boston/Harvard University. Then, Dummer spent an additional year of fellowship training with the Boston Adult Congenital Heart program at Children's Hospital Boston. The new program at Children's of Minnesota for adults with congenital heart disease will begin in January. It will be one of only a few in the United States. Adults to be served include:

- Those who underwent interventions on their hearts at a younger age;
- Those with congenital heart disease who have not had prior interventions on the heart.

The program will include a multi-disciplinary team of physicians and clinicians who will evaluate patients' entire well-being; outreach and education for adults with congenital heart disease as they transition from adolescence to adulthood; and participation in research to identify best practices with similar U.S. programs.

"Our goal is to help adults with congenital heart defects live healthy and productive lives," Dummer says. "In addition, there are an estimated 1 million adults living with congenital heart disease in the United States, and only a fraction of them are currently receiving medical care. We hope to serve a significant portion of that population who have been 'lost' to follow-up. These patients have complex issues and need specialized care."

At least 10 percent of all congenital heart defects are first found in adulthood. Defects are often discovered during pregnancy, when the heart is strained due to the increased volume of blood. Family practice and internal medicine physicians also discover them.

Interestingly, some patients seek help from psychiatrists, assuming that their feelings of fatigue are caused by depression or other mood disorders. Instead, the fatigue is caused by the aging heart succumbing after years of compensating for the congenital defect.

This program will add breadth to services offered by Children's cardiovascular cornerstone program. In 2005, Children's performed 252 minimally invasive procedures in the cardiac catheterization laboratory and 430 heart surgeries. Children's ranks high in results of care among top U.S. pediatric cardiology programs. For example, Children's mortality (death) ratio was second lowest in 2004 for cardiac surgery patients and was the lowest for non-surgical cardiac patients.

For more information, please contact:

- Children's division of critical care John Fugate, MD, medical director; Pamala VanHazinga, BSN, RN, clinical services director; or Mark Schumann, operations strategist, at (612) 813-6058.
- 🛚 Children's Heart Clinic Kirsten Dummer, MD, at (612) 813-8800. 🧡

From Amy's teen years to motherhood

By this point, pediatric cardiologist Greg Wright, MD, of Children's Heart Clinic, had become her pediatric cardiologist. Wynia still sees Wright for regular check-ups, and he followed her especially closely during her two pregnancies.

"Dr. Wright has transitioned me from my teenage years to motherhood," Wynia says. "It was reassuring to have him watch over me during my pregnancies and to let me know that my children's hearts were developing normally. He's a kind and caring man, and I'm glad to have him caring for me still to this day."

After her third surgery, Wynia again felt a surge of new energy and vitality. Even though she would always have a serious medical condition, her heart was strong enough so that she could keep up with her peers. She participated in cheerleading and "all the normal teenage stuff," Wynia says.

Today, Amy is thriving and living life to the fullest. She has a husband, Jonathan; two children, Ben and Grace; and a fulfilling job. She leads an active life and enjoys walking, swimming, playing outside with her kids, and riding a bicycle. Although she'll need specialized care for the rest of her life, Wynia has a normal life expectancy.

"Amy's story is the product of decades of clinical collaboration and innovation," Wright says. "She's one of many adults with congenital heart disease, and that's something we simply haven't seen in previous generations."

According to the Adult Congenital

Heart Association, about 1 million adults in the United States have heart defects that have been present since birth. There are now more adults than children living with heart defects.

This medical achievement creates its own set of questions: Who should care for these patients as they reach adulthood? Where should they receive care?

Training for adult cardiologists generally focuses on heart disease acquired during adulthood. They may be unfamiliar with these patients' unique anatomy and previous surgeries. Pediatric cardiologists, on the other hand, focus on patients under age 21 and practice in children's hospitals.

It may seem odd for adults to receive care in a pediatric hospital or clinic. But because of their expertise with congenital heart defects and treatments, pediatric cardiologists have much to offer this group of adults, especially if these specialists have additional training in adults with congenital heart disease.

Wynia understands the issues well. "When I sit in the reception area at Children's Heart Clinic, people probably assume that one of my children is there to see the doctor, not me," she says. "But I know I'm where I need to be. I know that Dr. Wright knows my situation and is the best one to care for me."

Giving back to the next generation of children

As a child life specialist, Amy works in the emergency department at Woodwinds Health Campus in Woodbury, a HealthEast community hospital that



Greg Wright, MD, a pediatric cardiologist at Children's Heart Clinic, has provided care for Amy Wynia for a number of years.

Photo by Scott Streble

collaborates with Children's to care for the pediatric population. She meets children as they enter the emergency department, developing a rapport and finding toys and activities to keep them occupied.

Wynia helps children during their entire visit, preparing them for medical procedures and, when possible, helping them make decisions to increase their coping skills. She loves it when children realize their courage in accomplishing difficult things at the hospital.

Every day, she draws on her memories of what it's like to be one of those children. "Being a child at heart and remembering what it's like to be a young patient—that makes me a better child life specialist," Wynia says. "I wear my scar like a badge of honor. It reminds me of how far I've come." *****

'Here, in our home'



A community hospice in Waconia, trained by Children's of Minnesota, helped the Rahn family to care for their son at home during the final months of his life.

By SALLY THOMPSON

ear the end of Jack Rahn's life, home was the right place to be.

Jack had serious medical problems during most of his life. His parents, Naomi and Jason, devoted themselves to making the most of their time together. In Jack's last months, the Rahns cared for him at home. Jack, age 5, died there in May 2004.

When a child like Jack has complex medical needs—or is dying—who helps a family to give care at home?

In the Upper Midwest, Children's Hospitals and Clinics of Minnesota takes a leading role. Children's has considerable expertise in this care and operates the only licensed hospice for children in Minnesota. Children's hospice was among the first in the U.S. for pediatric patients when it opened in 1978.

For families in the Twin Cities area, staff from Children's pain and palliative care program provide at-home and hospice care. For families like the Rahns who live outside the metro area, Children's role shifts to training and support for the home care and hospice providers in communities. These local providers gain the expertise to meet the special needs of children in their area.

Naomi and Jason Rahn, with their son, Calvin, cherish the memory of Jack, who died at age 5 in 2004.

Photos by Scott Streble



The team from Waconia who cared for Jack Rahn included Gwen Erdal, RN, left, and Pam Lamb, a social worker, of Ridgeview Home Health Services. Ridgeview's staff members have provided hospice care for several other children from the Waconia area. Through a one-of-a-kind program in the U.S., Children's has trained home care and hospice providers in nearly 30 communities in the five-state region, other states, and countries. (See article on page 10.)

Jack's story

Jack was born in Eugene, Ore., where Jason and Naomi attended graduate school. They remember him as a happy and outgoing child. By Jack's first birthday, his parents knew something was wrong. The Rahns searched for the cause of Jack's medical problems, consulting extensively with physicians in Oregon, the University of California, Los Angeles, and the Cleveland Clinic.

As a family, the Rahns participated in activities with friends who also had children with disabilities. Jack was a beloved member of this group. Their outings included traveling to the Oregon coast, walking along the river with friends, and picking strawberries. "We tried to do lots of things with Jack," Jason recalls.

The Rahns moved to Minnesota in 2003. Soon after that, they received the results of a test confirming Jack's diagno-

sis. He had mitochondrial disease, an unusual congenital condition. They understood that the disease was terminal and ultimately would take his life.

Mitochondrial disease affects a part of each cell called the mitochondria, which produce energy. The disease affected Jack's everyday body functions. He had uncontrolled seizures. His muscles weakened, so he used a wheelchair. And the disease affected Jack's digestion and absorption of food. He received nutrition through a tube implanted in his intestine. Even those feedings created cycles of painful digestive problems.

Jack received care numerous times at Children's – St. Paul, where he was hospitalized on both the pediatric epilepsy unit and a medical/surgical unit.

These hospital stays meant time away from the Rahns' home in Belle Plaine, located 60 miles southwest of St. Paul. Naomi recalls that this was a stressful time, especially after the birth of their second son, Calvin, in December 2003. Hospital stays meant that Naomi and Calvin would stay with Jack at Children's, while Jason remained in Belle Plaine so he could work.

Two conversations with staff at Children's convinced the Rahns that Jack's needs could be met closer to home. Children's physicians introduced the idea that Jack's medical care could be coordinated in Waconia, a 20-minute drive from their home. "That's when it sunk in that there was nothing more they could do for Jack's condition at Children's," Naomi says.

Naomi had a long visit with Jody Chrastek, RN, who coordinates Children's pain and palliative care program. "Jody was preparing me psychologically for caring for Jack at home," Naomi recalls. "She talked about hospice services. She also told me it was time to let people help us—people who offered to help out at home."

The Rahns chose Waconia pediatrician M.V. Srinivasin, MD, as Jack's primary physician. Chrastek connected the Rahns with the Ridgeview Home Health Services in Waconia.

Waconia's partnership with Children's

A few years earlier, Waconia's hospice providers had received specialized training from Children's of Minnesota. At the time, a Children's patient needed hospice care at home in Waconia. Children's could not provide care directly because the family lived outside the service area for Children's hospice.

Children's staff held educational sessions on the special needs of children for the Waconia staff. Leading this training were Chrastek and Stacy Remke, a social worker who coordinates Children's home care psychosocial services. In addition, Children's on-call nurses were available by phone 24/7 for Waconia's staff as they cared for the dying child.

Facts about palliative care and hospice

Children's Hospitals and Clinics of Minnesota operates an extensive program of home care and palliative care services for patients who live in Minnesota within 30 miles of Children's – Minneapolis or Children's – St. Paul. Children's operates the only licensed hospice service for children in Minnesota.

Children's is one of the largest pediatric programs in North America serving, on average, 60 to 90 patients a day in their homes. Children's staff who give this care include registered nurses, physicians, pharmacists, chaplains, child life specialists, and social workers. Care for children falls into two categories:

Palliative care: This begins at the diagnosis of a child's illness (with a physician's order) and continues throughout treatment. Patients are still able to pursue aggressive treatment to cure the disease. The emphasis is on providing the best possible quality of life for the child and family, offering the child comfort and management of symptoms, and helping families with the complex decisions they face.

Palliative care is appropriate for families who cope with a great deal of uncertainty about their child's condition. Often, the family benefits from coordination of the child's complex care that is offered under this program.

Many patients receive palliative care for a short time and return to their normal lives. Others shift into hospice care.

Hospice care: Cure is no longer an option for children who need hospice care. Yet, there is still much to be done to help the child and family enjoy each day, focusing on comfort and quality of life. This care brings together a multi-disciplinary team of professionals to manage the child's pain and symptoms and to support the family.

Children's was among the first pediatric hospice programs in the United States when it started in 1978.

Helping communities care for seriously ill and dying children

Throughout Minnesota and the Upper Midwest, children who have a life-threatening or terminal illness need care at home. Home is where children feel most comfortable, where families are together.

Children's Hospitals and Clinics of Minnesota is an important resource for communities when a child needs at-home care outside of the metro area.

Adults, often the elderly, are typical patients for community home care and hospice agencies. Requests for this kind of care for infants, children, and teens are unusual. When a call comes to work with a pediatric patient at home, nurses and other providers may feel unprepared.

Children's of Minnesota is sharing its expertise with communities in the five-state area. In 2003 - 2004, Children's received \$650,000 in federal funding to establish a pilot program that is one-of-a-kind in the United States.

Through Children's Institute for Palliative Care, health care providers in communities receive the training and support to meet the needs of families and children facing life-threatening or terminal illness.

So far, Children's has worked directly with health care providers in nearly 30 communities in the five-state region and other states and nations. "Hospice staff are already skilled in supporting the family," says Jody Chrastek, RN, coordinator of Children's pain and palliative care services. "We prepare them to do the work with children, and we help them gain the knowledge of pediatric care." There are many differences in caring for children who are seriously ill or dying, including assessing a child's pain, Chrastek explains. Often the child cannot talk, so caregivers need to work closely with parents to interpret the child's condition. The community connections of the child and family may be different from an adult's, including school, day care, and so on.

An important aspect of Children's support for outstate nurses and families is the 24/7 availability of Children's nurses from the pain and palliative care program. "That's important when you are the one on-call nurse who is trying to provide care, and no one else is available," Chrastek notes.

After a child dies, Children's offers a debriefing session for the nurses and staff who cared for the child. "These are very intense sessions," Chrastek says. "It's unnatural for a child to die, and the death of a child has a tremendous ripple effect in the community. This is part of our promise to 'be there' for community providers."

Children's Institute for Palliative Care offers formal educational conferences on pediatric care several times a year. Since 2003, more than 400 professionals from 80 agencies, health care systems, and educational institutions have attended. Tuition and training materials have been provided free of charge.

"There is a deep need for pediatric palliative care," Chrastek says. "When properly trained and supported, hospice staff caring for adults have the skills to provide this care for children in their own communities."



Jody Chrastek, RN, left, and Stacy Remke, a social worker, are the leaders of Children's Institute for Palliative Care, serving home care and hospice providers in the region. Since Jack Rahn's death, Waconia staff have provided hospice care for another child in the community. "Our interaction with Children's has increased the skills and confidence of our staff in working with children," says Janet Benz, RN, director of Ridgeview Home Health Services. "Through our partnership with Children's, we can provide this expertise for children in our community. For families, it's important that we are a local presence. Our staff are from the Waconia community."

Coordinating Jack's care at home

A care conference in Waconia was an important starting point for Jack's care at home. Naomi and Jason attended along with Srinivasin, Jack's pediatrician. Benz and social worker Pam Lamb represented Ridgeview Home Health Services, and ethicist Don Brunnquell, PhD, attended from Children's of Minnesota. They established lines of communication and discussed the care to be provided for Jack and the Rahns' wishes for him.

That meeting, plus an earlier discussion that Jason and Naomi had with Brunnquell, helped them to anticipate the difficult decisions they would face as Jack's condition worsened.

"It's unusual for families to deal with death and dying in children," Brunnquell explains. "There is an emotional impact when parents need to make these difficult decisions for a child." He helped the Rahns consider their beliefs and background and the benefits and harms of treatment. They discussed the possibility that treatments may be medically possible, but might not be long-term solutions.

Gwen Erdal, RN, of Ridgeview Home Health Services, coordinated Jack's care at home. She and other nurses formed the team that visited him several times a week and answered the family's calls by phone. A chaplain, a music and massage therapist, and volunteers from Ridgeview's hospice program also visited the Rahns.

"I felt Jack's care was more coordinated, and it felt safer for us to have the connection with Children's and their support," Naomi says. "I could call at any time day or night, and the nurses I spoke to from Waconia were familiar with Jack."

Jack's intestinal problems led to a hospital stay at Ridgeview Medical Center in Waconia. Jason and Naomi realized that Jack's digestive system was shutting down and could no longer process feedings. Choosing against further medical options, they took Jack home. His care shifted into hospice mode.

Home: the best place for Jack

"Before this, we had talked at length with Dr. Brunnquell about decisions we might face at the end of Jack's life," Jason says. "We already talked about what we wanted for Jack and what would be best. We did that at a time when we



Calvin Rahn accompanies his father, Jason, on the drums as his mother, Naomi, listens in.

Philanthropy supports palliative care and hospice services

A Chance to Dance fundraiser

A Chance to Dance – A Celebration of Life is a fundraising event supporting Children's hospice and Healing Quilt family bereavement programs.

The fall event on Sept. 30 was the fifth annual gala. It has raised \$102,300 since 2002. Hosted by Jonathan Yuhas, KARE 11 TV meteorologist, A Chance to Dance is a way for community members to support Children's hospice services, says Jody Chrastek, RN, coordinator of Children's pain and palliative care program.

Funds support unreimbursed services for patients in Children's pain and palliative care programs, including medications not covered by insurance, supplies for child life activities, and other means of increasing the comfort of children.

The next A Chance to Dance will take place in October 2007.

Bremer Foundation grant

A grant of \$32,632 by the Bremer Foundation in December 2004 supported efforts by Children's home care and hospice staff to extend its educational services into the five-state region.

"The Bremer Foundation provided funds for us to continue and expand the workshops and consultation activities in the region," says Stacy Remke, who coordinates Children's Institute for Palliative Care. "The goal is creating more opportunities for children to be served at home by community health care providers who are skilled in meeting kids' needs."

Children's seeks new funding for this program. Children's will continue these educational efforts for community providers, offering training at a nominal fee that will cover costs.





Playing with his train set is a favorite activity for Calvin Rahn. His parents, Naomi and Jason, have become advocates for hospice care. They cared for their son, Jack, at home during the last months of his life in 2004. were thinking clearly. We wanted him to be at home, and we did not want him in any pain."

Being at home with Jack was extremely important to the Rahns. "Jack was in his own bed, with the sights and smells of his own room. As a family, we had privacy and some semblance of our normal life," Naomi says. "Our families came to visit, to say goodbye. They could stay with us overnight without the worry of visiting hours and other hospital interruptions."

Naomi and Jason say that the nurses trusted them to read Jack's signals and under their guidance, to give him appropriate doses of pain medications.

For Erdal, Jack's primary hospice nurse, being able to reach Children's hospice nurses 24/7 gave her confidence. "I have many years of experience with adults in hospice and not as many with kids," she explains. "I called Children's several times a week during Jack's months of care."

Erdal was accustomed to caring for adults who could speak for themselves. "Jack couldn't communicate with us," she says. "Jody from Children's had explained that I would need to listen carefully and trust what his parents were telling me. It helped me to hear that from her."

Music brought a smile to Jack

Ridgeview's music therapist Katie Lindenfelser brought the most smiles to Jack. She visited every week, including the day before he died. As she played the guitar and sang, Jack sat in his wheelchair, shaking maracas. "Near the end, it was the only time he smiled," Naomi recalls. "Jack had always liked music. Katie had this gentle, soft-spoken way that he responded to." After the music, Katie gave Jack a massage as he fell asleep.

With these experiences, the Rahns have become strong advocates for hospice care. "We are in touch with other families who have seriously ill children, and we always mention hospice," Jason says. "We just explain to them what we did, that we had Jack at home and it worked well for us. It was not fun, but it was made better because we could be here, in our home."

Naomi talks about it this way: "Looking back, I would have wanted hospice care longer. Being at home helps your ability to process the situation. Jack had a good quality of life here at home, and that continued through to his final days."

Mary Kay Farrell, RN, is a key part of the Children's team that brought use of nitrous oxide to children. The gas, common in dentist's offices, is used at Children's during some procedures to reduce anxiety and pain. Photos by Scott Streble

`I had a dream_ a good dream!'

By SALLY THOMPSON

wited in her dentist's office for a routine teeth cleaning to start. She noticed a framed certificate for the dental hygenist's credentials to administer the gas nitrous oxide.

Nitrous oxide is commonly used in dental offices to help patients through uncomfortable procedures. It's a sedative that is safe, quick-acting, and mild.

"I thought, if a dental hygienist can give nitrous oxide to patients, why can't I?" says Zier, a specialist in caring for children in the pediatric intensive care unit at Children's Hospitals and Clinics of Minnesota. "I knew we could use it for our patients at Children's."

Zier pushed ahead with her goal of introducing nitrous oxide at Children's. She attended a two-day dental course on nitrous oxide at Tufts University in Boston. When Zier brought her knowledge back to Children's, she discovered an ally.

Mary Kay Farrell, RN, had long believed that nitrous oxide could help children in Children's radiology department, where she works. She believed it could ease the discomfort of some uncomfortable procedures. "The philosophy for adults of 'Just buck up and do it' doesn't work with children," Farrell says.

Together, Zier and Farrell started to tackle the many steps to bring this innovation to Children's. This included creating safety standards and training for staff, getting Children's of Minnesota introduces an innovative way to help children relax during uncomfortable tests and procedures. It's nitrous oxide, a crossover from the dentist's office.



Nurses help each child feel comfortable with the nitrous oxide mask before the procedure begins.





Mary Kay Farrell, RN, begins by talking about the upcoming medical procedure in terms the child can understand. Then, they place a nitrous oxide mask on a stuffed animal—Mickey Mouse in this case and the child selects a scent for the mask. equipment, and securing approval from the Minnesota Board of Nursing. Working with them were Denise Rucker, RN, of the radiology department, and Gloria Drake, RN, a Children's nurse anesthetist who is clinical services director of surgical services and perioperative care.

The group introduced nitrous oxide at Children's in 2004. This innovation makes Children's the only nurseadministered nitrous oxide program in the United States.

Nitrous oxide is now used for some procedures at Children's St. Paul and Minneapolis hospitals and at Children's West in Minnetonka. Many children receive it when they undergo a radiological test of the urinary system. For this test, a catheter is inserted into the child's bladder, the bladder is filled, and the child urinates into pads on the X-ray table while images are taken. Other children receive nitrous oxide when they need a needle inserted for an intravenous line or for nuclear medicine procedures involving a catheter and fluids.

Children, families give nitrous oxide rave reviews

Reactions from children and families are overwhelmingly positive. After a test ends, children often tell their nurses, "I had a dream—a good dream!" Nitrous oxide not only calmed them, it often erased any memories about the procedure.

For about 10 years Mary Stemper has brought her two daughters to the Children's – St. Paul radiology department for a bladder procedure. Rachel, now 13, needed the test several times before nitrous oxide was available. Luckily for Lauren, 5, she's had nitrous oxide for two tests.

"There is absolutely no comparison," says Mary Stemper. "Having nitrous oxide has made a night and day difference. It makes the whole procedure go more easily. You want that for your child, especially when they have to come back for the test year after year."

Facts about nitrous oxide at Children's of Minnesota

Here are questions that families often ask about nitrous oxide. Judy Zier, MD, and Mary Kay Farrell, RN, who introduced the use of nitrous oxide at Children's of Minnesota, provide the answers.

What is nitrous oxide?

Nitrous oxide is a sedative that is mild, fast-acting, and safe. It's a blend of two gases, nitrous oxide and oxygen. Nitrous oxide has a calming effect when it's inhaled. It reduces anxiety and pain, often causing people to forget the procedure.

What are examples of nitrous oxide's use at Children's?

- Radiology departments at St. Paul, Minneapolis, and Children's West campuses — for uncomfortable X-ray and imaging tests, such as CT scans.
- Hematology/oncology clinic at Children's -St. Paul — for spinal taps, IVs, and other necessary procedures.
- Emergency departments at Minneapolis and St. Paul hospitals — for stitching cuts, starting IVs in difficult situations, removing splinters, and orthopedic procedures such as setting bones.
- Special diagnostics department at Children's -Minneapolis — for tests of muscle and nerve function that require needle insertion; and Botox injections for muscle spasticity.

What are the side effects?

Children's research on 2,369 patients from September 2004 through September 2006 showed that nitrous oxide has few side effects. Only 6 percent of patients sedated with nitrous oxide experienced any, mainly minor, side effects. The most common were vomiting (3%) or nausea (2%). In comparison, up to 12 percent of patients have been reported to experience side effects from the oral sedative previously used for many of these procedures.

Before nitrous oxide, what did children receive as a sedative? Some patients received the sedative Versed, which

stayed in their systems for six hours and sometimes caused belligerent and combative behavior. Children who received Versed couldn't return to school after their test. Given the side effects, many parents decided against using Versed. Another sedative, Propofol, requires an IV for use, adding additional distress to the procedure.

How long do most children receive nitrous oxide during a test or procedure? Our average at Children's is 11 minutes. Children are monitored by a nurse at all times as they receive nitrous oxide. For longer tests or procedures, nurses adjust the amount of sedation based on the length of the test and the child's need for pain control.

How safe is nitrous oxide?

It's extremely safe. Among medical gases, nitrous oxide is considered to be very mild. Children's equipment to administer nitrous oxide is fail-safe, so an overdose is impossible.

Why has nitrous oxide been available only in dentist offices, not medical settings? Traditionally, dentists — not physicians — have been trained in the use of this gas. Although the first article on nitrous oxide use for general pediatric procedures appeared in the Journal of the American Medical Association 25 years ago, its use has remained in dentistry.

Is nitrous oxide used for medical care outside the U.S.?

Yes, it's used in Europe, Israel, and Australia.

What is unique about Children's program for nitrous oxide?

Our program is the only one in the United States in which registered nurses administer nitrous oxide, with the direction of a physician. Having nurses give nitrous oxide allows more patients to have access to it. Ongoing monitoring of the program ensures that nurse-administration of nitrous oxide is safe for kids.



Judy Zier, MD, left, and Mary Kay Farrell, RN.

We believe that our collaborative team approach, with physicians and nurses working together, has made the program an ongoing success.

Nurses have time to work with the children, such as helping children play with the nitrous oxide mask and showing them how the mask fits on a stuffed animal. When nurses work with children, we call nitrous oxide the "smelly I don't care medicine" or "giggle gas." Our approach helps kids lose their fear and feel more confident.

How is Children's spreading the word about nitrous oxide?

We'd like to see this used widely by medical providers for children and adults. In 2005, we made presentations at four national conferences on pediatric care. We are preparing two research studies for publication. Several physicians and nurses from around the country have visited our program to see the benefits for themselves. They are modeling their own programs based on our success.

Children's will host a seminar about our nitrous oxide program on May 4, 2007, at the Heart and Lung Center of Children's – St. Paul and United Hospital. We've designed this conference for physicians, nurses, and hospital administrators. For more information, please e-mail Catherine Hilby, manager of radiology, at catherine.hilby@childrensmn.org



Rachel, left, and Lauren Stemper have undergone yearly tests in the radiology department at Children's. Their mother, Mary, has helped them through the experience. Rachel had her tests before nitrous oxide was available; Lauren's are much more comfortable, thanks to nitrous oxide. Tests without nitrous oxide were very difficult for Rachel, and she was upset throughout them. "The nurses at Children's jumped through hoops to work with her, and I know it made their job harder," Stemper recalls.

In contrast, Lauren sailed through her test earlier this year. "She did have a few tears after the nitrous wore off, but they were tears of relief," Stemper says. "As a parent, it's very difficult to put my children through something that is painful or uncomfortable. Nitrous oxide relaxes the situation for everyone involved."

Katie Estes Collins echoes the praise for nitrous oxide. Her son, DeShawn, 4, receives treatment for cancer at Children's. Because his condition is followed carefully, he undergoes a CT scan every three months.

To start the sedative medication so DeShawn will sleep through the scan, an intravenous line—with a needle—must be placed in his arm. This involves "a poke," as he and his mother call it. DeShawn has experienced this with and without nitrous oxide.

"Nitrous oxide saves us. Now, our anxiety can be focused on the test results and his health, not the test itself."

Katie Estes Collins, parent

"We can tell him, 'No one likes a poke.' But Shawn is 4 years old," says Estes Collins. During DeShawn's latest test, his nurse had him take four deep breaths of nitrous oxide. "Oh, that's better," he said. Then, the nurse easily inserted the needle into his arm. When DeShawn awoke, his first words to his mother were, "Mom, I did it on the first try!"

Before nitrous oxide was available, DeShawn was tense and uncomfortable, and a second team of nurses was needed to start the IV. "That just created so much anxiety," Estes Collins says. "Nitrous oxide saves us. Now, our anxiety can be focused on the test results and his health, not the test itself."

Creating positive experiences, from the first time forward

1717172011

Zier and Farrell, the pioneers of nitrous oxide at Children's, find it extremely rewarding that they're helping so many children and families. They credit a collaborative team approach, with nurses and physicians working together, in making the program so successful. DeShawn Estes Collins and his mother, Katie, play with one of his favorite trucks. DeShawn is cared for in Children's oncology department. He has frequent CT scans, made easier by use of nitrous oxide.

Zier says it's important that each child's experience with a medical procedure be positive from the first time forward. "We want to make it the least distressing experience possible," she says. "Some of these children will need to come back and have the procedure every year."

Beyond her work in nursing, Farrell draws on her own experiences as a survivor of breast cancer. She's gone through some long, uncomfortable medical procedures without the benefit of sedation or distraction. That strengthened her resolve to improve matters for her young patients at Children's.

"Ethically, using nitrous oxide is the right thing to do," Farrell says. "If sedation does no harm and the pain does no good, then don't make people suffer." \neq

Simulation training on wheels

How do staff in hospital emergency departments and other critical environments stay up-to-date in caring for infants and children, when many of their patients are adults?

The answer involves keeping skills sharp for nurses, physicians, and other caregivers in the infrequent but critical emergency situations with children. And, Children's Hospitals and Clinics of Minnesota is part of the answer.

In 2007, a unique simulation center on wheels—a specially outfitted motor coach—will start rolling into hospital parking lots around the Midwest. A generous donation of \$634,000 by Kohl's Department Stores in July allowed Children's to purchase and outfit the simulation center.

Julie Gardner, senior vice president of marketing for Kohl's Department Stores, says this donation is part of the Kohl's Cares for Kids program, which promotes children's health and



educational opportunities. "We are committed to playing an active role in the communities we serve," Gardner says. "Kohl's is proud of the partnerships we've created with children's hospitals across the country. We are excited to join Children's of Minnesota in this endeavor."

In the center, pediatric experts from Children's of Minnesota will present scenarios of a child in distress. Emergency department staff work as a team to respond, assessing what's wrong and taking the right actions to stabilize the child. Actually, the child is a sophisticated computerized mannequin that mimics a child's symptoms of distress. Each exercise is videotaped, allowing staff to analyze their responses and find areas for improvement.

"Moving interactive training into the community represents the next generation of patient safety, and we are grateful for Kohl's generosity in helping to make this possible," says Julie Morath, MS, RN, Children's chief operating officer. "The ability to respond to a child in a medical crisis is an essential element of providing high-qualify, safe pediatric care for children. This donation helps Children's broaden our ability to share pediatric expertise."

This will be the first mobile simulation center in the United States to focus exclusively on emergency care for children. The respected Institute of Medicine (IOM) last summer highlighted the need to improve pediatric emergency care. Although children represent only 27 percent of all emergency department visits, the study noted that many hospitals need greater preparation to handle pediatric patients safely.

"Children represent a special challenge for emergency and trauma care providers, in large part because they have unique medical needs in comparison with adults," the IOM study noted. At Children's two emergency departments, staff practice regularly using simulations with computerized mannequins. Building teamwork and practicing in a no-risk setting are important benefits of simulation exercises.

Simulation also is used in delivery room scenarios for staff in Children's newborn intensive care units to sharpen team responses to an infant in distress. Medical resident training at Children's also benefits by exposing new doctors to possible emergencies and training them in best responses before they might face such situations in real life.

Planning is underway for activities at the simulation center in which families could learn ways to prevent accidents at home, says Karen Mathias, RN, a Children's advance practice registered nurse who is the center's director.



News briefs

Children's joins elite national group in nursing

Children's Hospitals and Clinics of Minnesota has achieved new heights in workplace excellence with the designation of Magnet status, which recognizes the best standards in nursing practice.

The designation in mid-October culminated four years of planning, including an exhaustive four-day survey by the American Nurses Credentialing Center (ANCC) to confirm Children's meets the exacting standards for Magnet designation. The ANCC, a subsidiary of the American Nursing Association, bestows Magnet status to "recognize health care organizations that provide the very best in nursing care and uphold the tradition within nursing of professional nursing practice."

Children's is the only Twin Cities hospital to achieve Magnet status and is the only Minnesota hospital system to provide comprehensive care exclusively to children. Only 4 percent of the 6,000-plus U.S. hospitals have qualified for Magnet designation.

"Earning Magnet status confirms what we already knew: The nurses at Children's are the gold standard," says Ginger Malone, MSN, RN, Children's chief nursing officer. "Our nurses care for children and families with an unparalleled sense of professionalism. They are at the heart of Children's commitment to providing the best pediatric care to all who come through our doors."

Malone gave particular kudos to the 38-member team of registered nurses who helped champion Children's efforts to gain Magnet status. Approximately 1,600 registered nurses work full- and part-time at Children's.

In 2002, The American Nurse, published by the American Nursing Association, described the impact of Magnet status in the workplace and for overall quality of patient care:

"A growing body of research indicates that the program is making a positive difference for nurses, their patients, and employers. For example, studies



Celebration was in order on Oct. 13, when Children's received news that it was awarded Magnet status in nursing. The team leading the lengthy Magnet application process included, from left, Paula McDonald, RN, Megan Thygeson, Keri Rateliff, RN, Magnet coordinator, and Mary Erickson, RN.

Photo by Scott Streble

indicate that patients experience lower mortality rates, shorter lengths of stay and increased satisfaction in Magnet facilities, while nurses also have increased satisfaction, as well as increased perceptions of productivity and the quality of care given. Employers benefit, too, as studies indicate that Magnet facilities have lower incidence of needlestick injuries, lower nurse burnout rates and higher retention rates, increased ability to attract new nurses, and higher JCAHO (Joint Commission on the Accreditation of Healthcare Organizations) scores."

The Magnet designation has its roots in a 1980s nursing shortage—a pattern that is re-emerging in U.S. health care. The American Academy of Nursing, also a subsidiary of the American Nursing Association, published a study that showed despite the shortage, some hospitals created an environment that allowed them to attract and keep well-qualified nurses. The ANCC formalized the Magnet concept in 1993 by establishing the Magnet Hospital Recognition Program for Excellence in Nursing Services.

Children's joins the Mayo Clinic and St. Cloud Hospital to become Minnesota's third health care provider to achieve Magnet designation.

Children's makes U.S. 'top-hospital' list for safety and quality



Children's Hospitals and Clinics of Minnesota was ranked among the top eight U.S. children's hospitals in a watershed survey of hospital quality and safety announced in October by the respected Leapfrog Group.

Children's and seven other pediatric institutions were listed as the best in the nation in the survey, which assessed hospitals for improvements that result in safer and higher quality care for patients.

This is the second year Children's has been listed as one of the top hospitals by the Leapfrog Group. A separate survey listed the 50 adult-focused U.S. hospitals that have made similar strides. Children's was the only Twin Cities hospital on Leapfrog's list.

"These results place Children's among the very best hospitals in the nation for safety and quality," says Alan L. Goldbloom, MD, president and CEO of Children's. "Moreover, the results reflect directly on the professionalism and skill of our dedicated staff, along with a strategic commitment to make long-term investments in safety and quality. Our patients and their families are the beneficiaries."

The Leapfrog Group focuses on a variety of improvements proven by research to make hospital care better. They include:

- Staffing in intensive care units;
- Use of computers that are linked to error-prevention software;
- Evidence-based hospital referrals, which measure results in high-risk procedures and care; and
- Safe practices based on a list of 27 events, developed by patient safety experts, that should never occur in a hospital.

Children's, for instance, pioneered the practice of having critical care physicians in its pediatric and neonatal intensive care units 24 hours a day. At Children's, 46 percent of hospital of beds are dedicated to critical care patients. The national average for pediatric hospitals is 26 percent and approximately 12 percent in adult institutions.

The Leapfrog Group represents a consortium of major employers



Becki Fust, left, and Katie Anderson, of Children's human resources department, sell Helping Little Heroes editions of the Star Tribune at the Mall of America.

Photo by Pam Trainor

responsible for purchasing health care coverage for more than 37 million Americans. It was launched in 2000, a year after the Institute of Medicine issued its landmark report on medical errors in U.S. hospitals.

Helping Little Heroes celebrates 5 years of fundraising for Children's

Special editions of the Star Tribune on Sept. 19 featured a full section about Children's Hospitals and Clinics of Minnesota. On Helping Little Heroes day, volunteers, employees, families, and supporters of Children's sold special editions of the newspaper, raising funds for Children's.

The 2006 event raised \$136,055. Since 2002, the Star Tribune's partnership with Children's has raised a total of \$728,054.

"We are extremely grateful for our partnership with the Star Tribune," says Alan L. Goldbloom, MD, Children's president and CEO. "The funds raised in five years are substantial and help us to better serve children and families. In addition, the newspaper supplement helps us tell Children's story to the public. Both causes are extremely important to Children's."

Discussions end on potential new children's hospital

Leaders discussing a consolidated children's hospital in the Twin Cities ended their discussions in September without reaching an agreement.

Leaders of Children's Hospitals and Clinics of Minnesota, Fairview Health Services and its University of Minnesota Children's Hospital, and Allina Hospitals & Clinics were unable to agree on a model that was both financially viable and workable for each organization.

It became apparent that the parties would be unable to pursue an independent, consolidated children's hospital without putting at risk the financial stability of some of the

News briefs

existing organizations and impeding their collective ability to continue delivering outstanding health care to the community.

"We knew when this process began that it would be an extremely complex undertaking," says Alan L. Goldbloom, MD, Children's president and CEO. "The discussions were open and constructive, but the outcome was disappointing for all. Nevertheless, we remain committed to building on our strengths and ensuring that children in this region receive care that is second to none."

Morath named Distinguished Advisor to patient safety board



Julie Morath, MS, RN

Julie Morath, chief operating officer of Children's Hospitals and Clinics of Minnesota, was named a Distinguished Advisor to the National Patient Safety Foundation (NPSF) in April.

The Distinguished Advisors represent the pinnacle of patient safety leadership and were elected by the NPSF board of directors for significant, visionary contributions to safer health care in the United States.

"Julie Morath's contributions to the field of patient safety are well known and her work at Children's and on a national level has set new standards for leadership," says Diane Pinakiewicz, NPSF president. "NPSF has been privileged to have her as a member of our board and is proud to confer this honor in recognition of her tremendous body of work in patient safety."

Westgate family establishes pediatric ethics forum

The first Westgate Pediatric Ethics Forum took place in October at Children's Hospitals and Clinics of Minnesota. The forum's focus was "Justice and International Pediatrics: Global Perspectives and Local Implications."

The forum was established to honor the work and contributions of Hugh Westgate, MD, and Alison Westgate. Hugh was the first director of anesthesia and intensive care at the former Minneapolis Children's Medical Center. He also served as chief of staff and a member of the first ethics committee. Alison was a long-time volunteer on the hospital's board, at Children's West, and at community organizations serving at-risk youth.

The couple's children created the forum to celebrate their parents' 50th wedding anniversary and to recognize their concern for the ethical care of children.

Electronic medical record progresses at Children's

Children's Hospitals and Clinics of Minnesota took a big step forward this fall in evolving from paper to electronic medical records.

In late September, Children's successfully launched the clinical documentation phase of this conversion. Caregivers began documenting daily patient care activities within the electronic medical record system, called PowerKIDS.

PowerKIDS provides authorized users at any Children's location with secure, easy access to each patient's health history, medical record, and health insurance information. It will also provide remote access for providers, physician offices, and families of patients.

"PowerKIDS gives us the tools to enhance the quality and safety of care that Children's delivers," said Bobbie Carroll, RN, director of clinical informatics and technology. "Our goals were to provide a platform for standardization and simplification–the cornerstones of patient safety–and to give the entire patient care team access to necessary information."

The last phase, called computerized provider order entry, will take place in 2007. Physicians and nurse practitioners will begin entering their orders electronically.

PowerKIDS has been created at Children's to provide faster and easier access to patients' medical information throughout the Children's system; to incorporate automated tools to create greater safety for patients; and to build in time-saving processes that will improve efficiency and care. *****





Children's - Minneapolis



Children's - St. Paul

Children's sites

Children's - Minneapolis

Hospital and specialty clinics 2525 Chicago Avenue South Minneapolis, MN 55404 (612) 813-6100

Children's - St. Paul Hospital and specialty clinics 345 North Smith Avenue St. Paul, MN 55102 (651) 220-6000

Children's Clinics - Woodwinds

Specialty and rehabilitation clinics in Woodbury 1825 Woodwinds Drive Woodbury, MN 55125 (651) 232-6800 (specialty clinics) (651) 232-6860 (rehabilitation clinic)

Children's - Roseville

Rehabilitation clinic 1835 West County Road C Roseville, MN 55113 (651) 638-1670

Children's West

Outpatient surgery and diagnostic center 6050 Clearwater Drive Minnetonka, MN 55343 (952) 930-8600

Rehabilitation clinic 5950 Clearwater Drive Minnetonka, MN 55343 (952) 930-8630

Affiliates:

Children's Foundation 2910 Centre Pointe Drive

Roseville, MN 55113 (651) 855-2800

Children's Physician Network 910 East 26th Street, Suite 420 Minneapolis, MN 55404 (612) 813-7436

Children's Internet address www.childrensmn.org

We're among the nation's best

In the top 4% of hospitals * in the U.S. for nursing care

Magnet recognition status awarded by the American Nurses Credentialing Center One of the 8
children's hospitals ×
in the U.S. for
safety and quality

Ranked by the Leapfrog Group, a consortium of major employers

At Children's of Minnesota, we're celebrating these awards, which show our excellence. We're the only hospital in the Twin Cities to receive these honors. Read more about it on pages 22-23.

Children's Hospitals and Clinics of Minnesota 2525 Chicago Avenue South Minneapolis, Minnesota 55404



NONPROFIT ORG

MINNEAPOLIS, MN PERMIT NO. 7629

CHANGE SERVICE REQUESTED



A child at heart

Magazine

Children's

Hospitals and

Clinics

•

Minnesota

Children's

Children's Mission

Children's Hospitals and Clinics of Minnesota champions the special health needs of children and their families. We are committed to improving children's health by providing high-quality, family-centered pediatric services. We advance these efforts through research and education.

Vision

Become one of the nation's best pediatric providers, accessible to all children.

Children's Hospitals and Clinics of Minnesota and Children's Foundation 2006 Board of Directors

James R. Ryan Chair, Hospital Vice Chair, Foundation Chair, Joint Executive Committee Chair, Quality Committee

Edward J. Phillips Chair, Foundation Vice Chair, Hospital Chair, Joint Development Committee

Ronald O. Baukol Treasurer, Hospital Chair, Joint Finance Committee

Sima Griffith Treasurer, Foundation

John R. Bultena Chair, Joint Investment Subcommittee

Michael K. Nation, MD Chair, Professional Staff Committee

Octavio Portu, Jr. Chair, Joint Audit Committee

William Weisman Chair, Joint Governance Committee

Raymond L. Barton Mark A. Cohn Peter J. Dehnel, MD David Estrin, MD Michael B. Fiterman Alan L. Goldbloom, MD Charles Levenberg Katherine Low David M. Overman, MD Sandra Sackett, MD Marvin S. Segal, MD Ronald White

Children's Hospitals and Clinics of Minnesota Leadership

Alan L. Goldbloom, MD President and Chief Executive Officer President, Children's Foundation

Julie Morath, MS, RN Chief Operating Officer

Jerry Massmann, MBA, CPA Vice President and Chief Financial Officer

Phillip M. Kibort, MD, MBA Vice President of Medical Affairs and Chief Medical Officer

David A. Brumbaugh, SPHR Vice President of Human Resources

Maria C. Christu, JD General Counsel

David S. Overman Chief Information Officer

Ginger Malone, MSN, RN Chief Nursing Officer

Michael K. Nation, MD Chief of Staff

Peter Dehnel, MD Vice Chief of Staff

Clark M. Smith, MD Chief of Pediatrics

Becky Bedore, MSN, RN Clinical Services Director, Pediatrics

David J. Schmeling, MD Chief of Surgical Services

Gloria Drake, MSN, RN, CRNA Clinical Services Director, Surgical Services and Perioperative Care

John H. Fugate, MD Chief of Critical Care

Pam VanHazinga, BSN, RN Clinical Services Director, Critical Care

Terri A. Hyduke Chief Executive Officer, Children's Physician Network

Children's Magazine Vol. 8, No. 1

© Copyright 2006 Children's Hospitals and Clinics of Minnesota

Published by Children's Hospitals and Clinics of Minnesota, Communications and Public Relations Department, Suite 216 South, 2550 University Ave. W., St. Paul, MN 55114. Phone (612) 813-6618.

Sally Thompson Editor

Stanley Wai Graphic designer

Mark Heymans Communications and public relations director

Audrey Anderson Corporate communications manager

Scott Streble Pam Trainor Brady Willette Photographers

On the cover: Amy Wynia and her children, Grace and Ben, enjoy a fall day at a park. Wynia was born with a serious heart defect and had several surgeries during childhood. Children's cardiovascular program is developing a new program to serve the special needs of adults like Wynia with congenital heart disease.

Cover photo by Brady Willette

