Connected care

Maternal-fetal medicine and neonatology teams forge close partnerships to care for mothers and their babies

Expecting her second child earlier this year, Tricia Paulson had no reason to believe this pregnancy was going to go any less smoothly than her first go-around. But an ultrasound at 17 weeks showed a concerning shadow on one of her baby’s lungs, and her obstetrician suggested she receive a level II ultrasound at Fairview Ridges Hospital in Burnsville.

That screening at 20 weeks uncovered a mass on the baby’s lung. Though doctors suspected that the tumor was benign, it still put the baby at risk. Masses like these often continue to grow with the baby, impeding their developing lungs and causing heart failure, notes Tracy Prosen, M.D., a maternal-fetal medicine physician at University of Minnesota Medical Center in Minneapolis, who took on Tricia’s medical care.

That was the case with baby Emmeline, whose constantly growing tumor crowded her chest and pushed on her heart.

And so began Paulson’s long journey throughout the remaining months of her pregnancy. During a 10-week period, she had seven

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procedures during which Prosen placed thoracoamniotic shunts in Emmeline’s chest to drain fluid from the mass. Then when Paulson’s water broke at 30 weeks, she spent nearly seven weeks on bed rest at The Birthplace at University of Minnesota Masonic Children’s Hospital.

“Our worry was that this mass was still very large and taking up space in her chest where the lungs would normally grow,” says Prosen, who directs the University’s Fetal Diagnosis and Treatment Center. “This was a baby whose life was in danger at multiple times during the pregnancy and in the hours, days, and weeks after birth. We were going to do everything in our power to give her the best chance possible.”

After Emmeline was born in late May, she was intubated for respiratory failure, then admitted to the neonatal intensive care unit (NICU) at University of Minnesota Masonic Children’s Hospital—just steps away from the just-renovated Birthplace (see page 4.) Because of her cardiorespiratory instability, neonatologist Kari Roberts, M.D., and pediatric surgeon Donavon Hess, M.D., put Emmeline on heart-lung bypass. Two days later, surgeons removed one lobe of her lung and the tumor, which had grown to the size of a computer mouse—huge in a 7-pound, 1.5-ounce baby.

Emmeline spent the first months of her life in the NICU, eventually coming off of bypass and learning to breathe on her own.

Well-orchestrated care

It’s been a stressful time for the Paulson family, to say the least, but some of that stress was eased by the medical care Tricia and Emmeline received at the University.

“I’m just glad that we had the University of Minnesota and people who had the expertise to deal with this,” says Paulson, who lives with her husband, Ryan, and 3-year-old daughter, Joey, in Rosemount, Minnesota. “It made it a little easier knowing that we were in good hands.”

It also helped knowing that Prosen was orchestrating their care among a large team of health care professionals.

“To have everyone in one place was really great,” Paulson adds. "Knowing that they have worked together before and trust each other and were all on the same page going into this was a relief. They all knew the plan, and they were all going to take care of us.”

Strong links

Such coordination of care is the norm at University of Minnesota Masonic Children’s Hospital. When maternal-fetal medicine physicians treat women who have complicated pregnancies or babies who have abnormalities, they partner closely with all of the people who will take care of the newborns once they arrive.

The U’s Maternal-Fetal Medicine Center is physically connected to the children’s hospital as well. And when high-risk babies are born, the hospital’s neonatology team is at the ready.

It’s a key part of the University’s success with providing leading-edge care to moms and babies, helping it garner rankings among the nation’s best neonatology services—and as the highest-ranked neonatology service in Minnesota—by U.S. News and World Report this year. Strong physical and professional links among specialists help teams offer seamless care to their patients.

“When we call for a NICU team during a delivery, they are there in under a minute,”
Thomas George, M.D., a neonatologist and medical director of the U of M Masonic Children’s Hospital’s NICU, helped plan for Emmeline’s birth. Providing such coordinated, comprehensive care is a big part of his job. It’s something the University has been doing for years because it puts parents at ease and helps the medical team provide the best outcomes.

“I really leads parents to have a sense of confidence that we’re ready to take care of their baby as a team. It truly is a village,” says George. “We want to ensure them that we’ve thought of everything to prepare for their babies.”

Other medical centers have adopted the University’s model of caring for high-risk mothers and babies, George notes. Last fall, the U introduced electronic fetal medical records so that each person who is, or will be, involved in the care of the mother or baby may access the record any time it’s needed.
The Birthplace at University of Minnesota Masonic Children’s Hospital just underwent a top-to-bottom, $21 million renovation project designed to create a warm, welcoming mother- and family-oriented experience.

In rooms that look more hotel than hospital, top-of-the-line upgrades are bringing added comfort to patients and families in the The Birthplace’s Labor and Delivery Unit, Pregnancy Special Care Unit, and Newborn Family Care Center.

If needed, patients also have access to expert care from a wide spectrum of specialists, giving expectant mothers and their families peace of mind and body.

“We have been providing high-quality, state-of-the-art, evidence-based care for mothers and children,” says obstetrician-in-chief Daniel Landers, M.D. “Now we are doing it in a setting that matches our care commitment, in an environment that is soothing, promotes healing, and supports bonding among mothers, babies, and families.”

When the U of M Masonic Children’s Hospital building was completed in 2011, its top floor was left unfinished. Leaders saw the space as an opportunity to create an innovative care experience for mothers and babies. The floor was completed in August and now houses 24 postpartum rooms.

For newborns who need advanced care, there’s a newly renovated and expanded Level IV Neonatal Intensive Care Unit nearby as well. It now has capacity for 62 babies, and it includes 11 new private rooms—two designated for twins—for families preparing to transition home.

‘First-class experience’ for a front-line family

John Harris Sullivan was welcomed into the world at the Newborn Family Care Center at University of Minnesota Masonic Children’s Hospital. The 6-pound-13-ounce, 21.25-inch baby was born August 4 to Ariel and John Sullivan.

“It’s not possible to put into words how fortunate we feel to have received this incredible gift of a healthy, beautiful baby boy! We are so thankful for the amazing staff at University of Minnesota Masonic Children’s Hospital,” says proud father John Sullivan, center for the Minnesota Vikings, who was comforted to know that the hospital always has a team of specialists at the ready, just in case. “It was a first-class experience.”
Most of the time, they prayed on their knees next to their daughter’s hospital bed. Sometimes, they prayed before a statue of Mary on the hospital grounds. Rarely, when there was a good time to sneak away, they found a quiet moment inside the chapel in the adjacent affiliated hospital.

But while Marc and Mandy Seymour stayed with their infant daughter at the then-brand-new University of Minnesota Masonic Children’s Hospital building, there was no chapel on site.

Quinn Rosalie Seymour was born August 9, 2011, in Ohio with junctional epidermolysis bullosa (JEB) Herlitz-type—a severe subtype of what has been called “the worst disease you’ve never heard of.” Its hallmark characteristic is extremely fragile skin that blisters or sloughs off with even minor friction from rubbing, scratching, or changing clothes. The blistering also affects the body’s mucous membranes, making eating and digesting food painful and sometimes impossible.

Within days of Quinn’s devastating diagnosis, the Seymours learned about the experimental treatment pioneered at the University of Minnesota aimed at treating EB with a promising but risky blood and marrow transplant. So the Seymours packed up and temporarily moved to Minnesota when Quinn was 11 weeks old, seeking care from EB trailblazer Jakub Tolar, M.D., Ph.D., a pediatric oncologist and director of the University’s Stem Cell Institute.

Quinn struggled with multiple bouts of pneumonia after her transplant. On April 7, 2012, 8-month-old Quinn passed away, surrounded by her family, including her then-2-year-old brother, Camden.

Through her grief, Mandy Seymour kept thinking about a conversation she’d had with the hospital chaplain several months earlier. The chaplain had told her that the hospital was supposed to have a chapel but that no donor had yet stepped forward to help build it. “It was always on my heart,” Mandy Seymour says.

Soon the Seymours had made it their personal goal to build out the chapel in Quinn’s honor—a $500,000 project.

Three years, many fundraising events, and several generous donations later—including significant gifts from grandpa Dale Seymour as well as another local family—they reached that goal, just as they were deciding to move to Minnesota permanently.

The Seymours say the hospital will always hold a special place in their hearts—not only because it was where Quinn spent almost all of her life, but because they found a place full of people who wanted their daughter to live as much as they did. The hospital community lifted them up in their time of need, they say, and they hope that the Quinn Seymour Chapel can do the same for others following in their footsteps.

“It’s not about us,” Marc Seymour says. “It’s about providing a place where people can find a little bit of comfort and a little bit of hope.”

When it opens in 2016, the chapel will provide a nondenominational space for anyone in search of a moment of prayer or peace.
For Masonic Cancer Center scientists Branden Moriarity, Ph.D., and David Largaespada, Ph.D., it’s about the Wyckoffs, the Sobiechs, and thousands of other families who are all too familiar with osteosarcoma and its devastating effects.

These families fuel the researchers’ passion to cure this often deadly form of bone cancer. And they just became a little closer to that goal.

A new mouse model developed at the Masonic Cancer Center has revealed the genes and pathways that, when altered, can cause osteosarcoma. The information could be used to improve treatment targets for future patients.

Their discoveries were published in the journal *Nature Genetics* in May.

“Human osteosarcoma tumors are so genetically disordered that it is nearly impossible to utilize the usual methods to identify the genes associated with them,” says Moriarity, an assistant professor in the University of Minnesota Medical School’s Department of Pediatrics. “This model offers the first opportunity to identify and understand the genetic drivers of osteosarcoma on a broad scale.”

The research was funded by the Karen Wyckoff Rein in Sarcoma Foundation and the Zach Sobiech Osteosarcoma Fund of Children’s Cancer Research Fund, as well as the National Cancer Institute and American Cancer Society.

“Philanthropy played a major role in helping us to establish the mouse model we used,” Largaespada says. “Moreover, we used philanthropy to study specific osteosarcoma genes further. Without these funds, we could not have gone as fast or as far in this work, perhaps delaying delivery of new cures to patients.”

The scientists’ genomic analysis uncovered several osteosarcoma genes that make proteins that could be targets for therapies in the future. The genes SEMA4D and SEMA6D were found to be expressed at high levels in more than half of all human osteosarcomas.

“SEMA4D seems to cause many human osteosarcomas to grow out of control,” says Largaespada. Inhibiting the expression of that gene could help stop the growth of osteosarcoma, he adds.

The U of M team’s progress brings hope to many of those who have seen this “horrible, ugly disease” firsthand, says Laura Sobiech, whose son Zach died of osteosarcoma in 2013.

“They are the superstars that nobody knows,” she says of the researchers. “They are in this for reasons that go so far beyond just recognition. They truly care about these kids. ... I have hope now, and it’s because of that team.”

Pete Wyckoff, whose daughter, Karen, died of sarcoma in 2001, agrees that it’s easy to support this team of “bright, committed researchers” whose hearts are in the right place.

“We’re very proud that we were in on the ground floor to help make this idea happen,” he says.

**SAVE THE DATE**
Show your support for University of Minnesota Masonic Children’s Hospital on Give to the Max Day.
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When University of Minnesota Masonic Children’s Hospital started offering regular yoga sessions for its behavioral health patients, it didn’t take long for caregivers to notice a huge difference. During therapy sessions right after they finished a Yoga Calm® class, the teenagers were more relaxed, less anxious, more focused, and better able to participate.

Many of the kids in the hospital’s Child and Adolescent Mental Health and Intensive Treatment Center are grappling with anxiety, depression, psychosis, substance abuse, and other emotional and behavioral disorders. Nurse specialists and administrators who do yoga had heard of the Yoga Calm program and its success in Twin Cities schools, and they wanted to see if it would be effective for their patients.

Led by certified instructors, Yoga Calm combines yoga movements with mindfulness, relaxation, emotional skill development, nervous system regulation techniques, and aromatherapy. The program reduces patients’ anxiety and agitation, while also helping them calm their nervous systems, which then leads to strong progress in therapy, says Susan Heitzman, a clinical nurse specialist and advanced practice nurse leader in the hospital’s child and adolescent behavioral services.

In 2010, the hospital started offering Yoga Calm weekly with a grant from the University of Minnesota Foundation. Then it secured a $10,000 grant from Covidien Cares, the philanthropic arm of the medical device company, recently acquired by Medtronic, to expand its program to twice-weekly sessions for adolescent patients on three units: the dual-diagnosis program for teens with chemical dependency and mental health issues, the intensive treatment center for the most acute patients, and the child adolescent mental health unit. Depending on the unit, two to 15 patients participate at a time.

The hospital wants to continue expanding its Yoga Calm offerings to daily sessions for behavioral health patients because it’s so effective, says Karen Wendt, program director of the behavioral health unit. Currently a medical student from the University volunteers on Wednesday nights to provide an additional class, but patients are asking to have it available every day.

“That’s some of the feedback we’re getting from the kids: ‘We want more yoga,’” says Wendt. When class is over, instructors often ask the teens to write down what they are feeling. “The biggest theme is, ‘I feel calmer, I feel better, I have hope, I love it.’ It’s been very powerful.”
Cheers to you!

Thanks to you, more children are thriving in Minnesota and around the world.

Together, more than 14,000 supporters raised $220 million for our Children’s Health Campaign—far surpassing our $175 million goal. We:

- outfitted 37 Adopt A Rooms with special features that make University of Minnesota Masonic Children’s Hospital feel more like home.
- established 43 funds for patient and family programs and emergency assistance.
- raised $75 million for children’s health research and education.

To learn how you can be a champion of children’s health, contact Elizabeth Patty at patty@umn.edu or 612-625-6136.

Cheers to you!