### Celebrating 20 Years of Nationwide Children's Family Advisory Council

Thanks to our technology-driven world, you've probably used one of the cell phone charging stations throughout the hospital. Did you know Nationwide Children's Family Advisory Council (FAC) helped to put the stations in place? This is just one of the many improvements the FAC



Covered parking: The FAC was a major advocate for the construction of covered, accessible parking. With our unpredictable weather, this was a significant benefit for families juggling children, strollers, wheelchairs and medical equipment.

has put into place since its inception 20 years ago. The hospital committee began in February 1998 as a way to ensure patient and family-centered care and improved customer service are always present between families and staff.

Currently, FAC has 49 members: 41 parents and eight Nationwide Children's staff. Meeting monthly, the group provides input on hospital initiatives, develops projects for program enhancements and advocates in the community.

As the FAC celebrates its 20th anniversary, we're sharing some of the other ways the group has positively impacted the hospital.

**Design of the 2012 hospital addition**: As the new hospital tower was being built, the FAC was consulted for patient and family input. The members were shown mock-ups, and even former members provided ideas and thoughts.

Partners in Care, Partners in Hope Award: It was the FAC that came up with this annual award, which is presented to a Nationwide Children's staff member who goes above and beyond with family-centered care. Each year, employees are nominated by families, and the FAC votes on the award recipient.

[Continued]

#### IN THIS ISSUE

Celebrating 20 Years of Family Advisory Council	1-2
A Parent's Perspective	2
Home Medical Equipment Store	3
Worth the Watch	3

Partners in Care, Partners in Hope Award Nominations	'
On Our Sleeves Campaign	





Cookies & Conversation: FAC parents and other parent advisors will talk to current parents, answer their questions and share important hospital information through this initiative, where they'll go room to room... with cookies, of course!

**Gift cards:** Did you know the hospital has family gift cards? Another FAC-created project, the gift cards can be loaded by anyone and given to patients and families. They can be used for food in the cafeteria, gift shop and more.

Visit NationwideChildrens.org/Family-Advisory-Council to learn more about the group and its impact.



Past Family Advisory Council chairs gathered to celebrate and share stories during the Anniversary Celebration on September 11, 2018.

PICTURED ON PAGE 1: The 2018 Family Advisory Council.

## A Parent's Perspective: Speak Now for Kids

Sarah Lodge, Parent

This June, our family had the opportunity to travel with Nationwide Children's Hospital to Washington, D.C. for the Children's Hospital Association Speak Now for Kids Advocacy Day. Nearly 50 families representing children's hospitals across the country rallied together to speak to our Senators and Congressmen about the importance of healthcare for

children, Medicaid, and CHGME, a graduate student medical education program.

Our family had a fantastic time traveling to D.C., visiting the national monuments and sharing our story. Our son Logan, age 4, was born with profound hearing loss and chronic immune thrombocytopenia. He wears bilateral cochlear implants. We see many clinics throughout Nationwide Children's Hospital for his various health needs. Living in Columbus, we are fortunate to have quick and easy access to a variety of exceptional pediatric specialists. However, we realize many families are not so lucky- and that is why we wanted to speak to our legislators regarding the need for all children with medical needs to have access to the best and most specialized care available.

Speak Now for Kids was an amazing experience for our family and we are grateful that we were able to attend. We met families from across the country and my kiddos made many new friends. Together, I know that all of these kids and families made a tremendous and lasting impression on our members of Congress.



Logan with his new superhero friends at Speak Now for Kids in Washington, D.C.

# Home Medical Equipment Store Provides Easy Access for Families

Did you know Nationwide Children's has a Home Medical Equipment store? Located in Lewis Center, all our equipment meets the special needs of newborns, infants, and children who have acute or chronic medical conditions. When medical equipment is needed, one of our pediatric nurses or equipment staff demonstrates proper use.

Nationwide Children's staff member Gary Hosfelt has been managing Home Medical Equipment for the hospital for the past 12 years, and he and his team will even make home visits when necessary.

Gary recently shared the story of how he helped craft a custom bed for a patient:

"We had a call about a special bed that a mom saw online. It was very expensive - that bed was a high- sided wood crib. The child chewed wood, and Mom and Dad were getting no sleep because the child was getting out of bed every night. She found this crib that has a top on it and said it would be the perfect thing.

We got approval through the insurance to help them with the financing. When we got it, we realized the child is also a climber. He would get out of the top of the crib, and now with him being high up, he would drop down to the floor and run around the house. We obviously couldn't put a locking top on it, so I had to get creative.

I called the manufacturer, and found that a higher crib would cost more. The manufacturer told us we should have ordered the higher crib from the beginning, but I let them know we couldn't give up the bed we had.

A tech and I were at the house, and the child's mom took pictures and had the manufacturer on the phone. We got them to agree to send the higher extensions to us, and we were able to get it put together. Now the crib is only six inches from the ceiling, and his mom and dad are sleeping again.

In the process, we learned about the beds and we were able to put an IV hook on the bed. That wasn't something the manufacturer offered. We had from the first bed install to the end of it, probably 8 or 9 different trips back to the home to make the child safe – we have the flexibility to do what other people can't. I talk to mom every once in a while and they are so thankful that they are able to sleep again."

Thanks to staff like Gary, Nationwide Children's is able to provide best outcomes to patients and families.

Want to visit the Lewis Center store? It's located at 7853 Pacer Drive, Delaware, OH 43015.

Visit NationwideChildrens.org/ Specialties/Homecare/Home-Medical-Equipment for store hours and more information.



Gary Hosfelt manages Nationwide Children's Home Medical Equipment.

### Worth the Watch

You're about to meet first time parents who spent months on a diagnostic odyssey. Traditional testing couldn't give them a clear diagnosis for their daughter, Charlie. Dr. Kim McBride suggested genetic testing and that's when Charlie's life changed for the better.

Visit Nationwide Children's YouTube channel and search Charlie to watch a video of her story.

# Partners in Care, Partners in Hope: Family Advisory Council's Award of Excellence in Family Centered Care

The Family Advisory Council at Nationwide Children's Hospital is pleased to announce the annual Partners in Care, Partners in Hope Award of Excellence in Family Centered Care.

This award will be presented to an employee, health care provider or department of Nationwide Children's Hospital in recognition of their outstanding achievement in care that reflects excellence in the core concepts of family centered care. Patients and/or family members of patients who have been treated at Nationwide Children's are invited to submit nominations.

Core concepts and criteria by which nominees are judged:

**Dignity and Respect** – Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

Information Sharing – Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.

**Participation** – Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

**Collaboration** – Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation: in health care facility design; and in professional education, as well as in the delivery of care.

The Partners in Care, Partners in Hope Award will be given at the Annual Employee Recognition Dinner and Awards Ceremony in January. Nomination forms are available in the Family Resource Center or online. The deadline for nominations will be November 30, 2018.

Recipients will receive a beautiful piece of artwork designed and created by a local artist with a connection to Nationwide Children's Hospital. Selection will be by the Partners in Care, Partners in Hope Award Committee composed of patients, caregivers, family members and select staff members. The award will be announced and presented in early 2019.

Visit NationwideChildrens.org/Partners-in-Hope-Partners-in-Care to learn more.

# On Our Sleeves Campaign



Because kids don't wear their thoughts on their sleeves, Nationwide Children's Hospital launched the *On Our Sleeves* campaign, a movement to transform children's mental health. The statistics are sobering – 1 in 5 children in our community is living with a mental illness. Yet, pediatric mental health research is vastly underfunded. That's why we're making mental health care and research a priority. For more information, including tips for how to talk to your children about mental health, visit **OnOurSleeves.org**.