

Complex Health Care Team

Dr. Garey Noritz, Complex Health Care Team

Patients with complex problems need services that are holistic, coordinated, continuous and family-centered. The patient and family are the most important drivers of the care team, which may include an extensive network of specialists. The Complex Health Care Team will help the patient and family achieve the best possible state of health and quality of life by working with all members of the team.



patients, we act as consultants to the primary care provider. Since we are on campus and have quick access to the specialists at Nationwide Children's Hospital, we can help the PCP and family organize care. When patients are admitted to the hospital, we try to have regular contact with the inpatient team to make sure that all needs are being met and that all questions are being answered.

We are a "medical home" for children and adults with neurodevelopmental disabilities. Patients and families with these types of challenges are often faced with a bewildering array of specialists, recommendations, and choices. Our patients commonly face functional limitations with neurocognitive delay and technology dependence that place them at greater risk for frequent hospitalizations. We will help patients and families be the most informed users of medical services; avoid duplication; and make care choices in keeping with their goals and goals for their children. For some patients, we do primary care well checks, immunizations, sick visits, and so on. For other

The strength of our program is our accessibility and our team approach. Patients can usually be seen the same day or next day for urgent needs. We are available for phone calls evenings and weekends. Our team is large and we all have specific areas of expertise to help families. Medical care is provided by physicians and nurse practitioners with experience in the care of patients with neurodevelopmental disability. For most visits, a dietician and social worker are available. Nurses, case managers and clinic staff work behind the scenes to answer questions, process paperwork and keep the team moving.

Appointments can be made by calling (614) 722-5808. Referrals are preferred but not necessary.

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Connecting Families: One Family at a Time

Meredith Brink, MSW, LSW, Connecting Families Program Coordinator

Imagine your child has just received a new diagnosis that you know very little about. Imagine your family's lives have been changed as you have just learned of your child's chronic health condition. For many of you, these scenarios are realities. Now imagine you have the opportunity to talk with another family who has experienced those same feelings of anxiety, helplessness, and fear—another family who can help “normalize” your situation.

Have you ever just wanted to talk to another family who has been in similar shoes? Talk with someone who also has a child diagnosed with diabetes or a heart condition or speak with a family whose child also has a feeding tube or is oxygen dependent?

Connecting Families Mentor Program began officially in March of 2013 as part of Nationwide Children's ongoing commitment to family-centered care. Our mission is to create family-to-family partnerships that promote healthy lifestyles and enhance the quality of life for the child and for their family.

We would like to share feedback from some of our mentors. For example, Kelly feels that having the ability to share stories and receive emotional support from another family can be invaluable.

“My experience as a Connecting Families mentor has been wonderful because I am able to share information and experiences with families that may make their situation easier to deal with,” Kelly said. “I can let them know that they aren't alone.”

Volunteer mentors receive training to provide peer support from the perspective of “been there, done that”. Mentors help navigate complex health care systems because they are experts in their child's care, wanting to provide their gained knowledge to families who are just getting started.

When Amanda's son was born with a congenital limb anomaly she felt helpless, confused and lost. In her family's time of uncertainty she sought out other parents of children with diagnoses similar to her son's because talking with those families was reassuring, helpful and inspiring. As a Connecting

Families mentor, she has found the opportunity to give back to other families the support she received when her son's diagnosis was so new to her.

“There is remarkable hope and strength gained from developing a sense of connection and community with someone whose trials are similar to your own,” Amanda said. “Perhaps that parent can look at our family and our son and know that it will be ok.”

Connecting Families now includes 200 families, referred by medical specialty areas, families, schools and community agencies. We have trained young adult mentors living with a diagnosis as well as adolescents wanting to help a fellow teenager. We have siblings, grandparents and foster parent mentors. We have trained mentors who speak Spanish, Somali, Arabic and American Sign Language. Connecting Families provides the opportunity for families to be linked based on like diagnoses, new treatments and similar life issues.

Lynne has been a mentor for several families whose children's diagnoses are similar to her daughter's, and she has also been a tremendous support to families struggling to navigate the school system and the IEP process.

Lynn believes that no matter the commonality that links families, *“One-on-one, through phone calls, emails, at clinic visits, while inpatient or the occasional coffee house chat, we can really make a difference for one another.”*

Mentee Feedback:

“We cannot imagine moving forward with my child's upcoming surgeries without the reassurance we received from our mentors. To see a very happy three year old with incredible speech abilities after three cleft surgeries gave us hope and determination to meet the same targets.”

If you are interested in becoming a Connecting Families Mentor, please complete an application on our website, NationwideChildrens.org/Connecting-Families. If you would like to have a mentor, call (614) 722-6747. If you have questions or just want more information, please email Meredith Brink at ConnectingFamilies@NationwideChildrens.org

Every family deserves the opportunity to connect with someone who has walked a similar path and to be reminded family-to-family support matters.

American Health Packaging Partnership

On January 15, American Health Packaging kicked off a new partnership with Nationwide Children's Hospital. We cannot thank the employees and company enough for their donation as well as the time and effort it took to make each care kit. Their contribution has been overwhelmingly embraced and appreciated by each family that has received one.



Karly Elliott from American Health Packaging recently released the following press release.

American Health Packaging, a Columbus, Ohio health care organization, recently engaged its associates in a community outreach initiative to benefit the Nationwide Children's Hospital Family Resource Center.

The program will provide essential personal care item kits to patient families through the Family Resource Center. During the kick-off event, American Health Packaging Associates created more than 1,800 "We Care Kits." Annually, American Health Packaging will pack and donate approximately 3,600 kits for families visiting Nationwide Children's.

The event was attended by American Health Packaging staff, Nationwide Children's patient Brett Kinglsey, his mother Allison as well as Family Resource Center coordinator, Paul Seese. Paul said, "having these care kits available for families is going to be a phenomenal support." Allison Kingsley shared a brief thank you with the American Health Packaging staff, calling the care kits "a blessing" for patient families.

As a health care organization, American Health Packaging is committed to sponsoring programs such as this, so that we may not only impact our community but also provide the opportunity for staff to get involved in giving back. "We are a health care company and part of our mission is to make people better. This is a way to demonstrate that community involvement and community spirit," said Rick Knight, vice president and general manager of American Health Packaging. "We believe that every child deserves the chance for a healthy future and their family deserves our support on this journey towards a happy and healthy life. This program will help to make that journey a more comfortable one."

COSI and NCH/CDC Partner to Offer Autism Activities

Amy Hess, Autism Treatment Network Site Coordinator



The Center for Science and Industry, COSI, has been a very active supporter of children and families with autism in our community. In 2013, they offered two Autism Awareness and Activities events at their facility and, in 2014, they will hold three events focusing on improving access to services, education and technology.

In addition to the events, COSI has completed renovations for a calming room that can be used by COSI visitors with autism who may become overwhelmed while visiting COSI. This room will allow guests with autism a safe location away from the crowd to calm before continuing with their COSI experience.

It was recently announced by the Autism Speaks board of directors that COSI has been awarded a Family Services Chapter Grant for the proposal: Video Modeling the COSI Experience.

The video modeling project will offer individuals with autism increased access to the COSI museum and exhibits through the development of video tutorials. These videos will allow individuals with autism the opportunity to see and learn about the exhibit prior to the experience of attending in person. This is part of the “*See it, Learn it, Live it*” project in conjunction with the Autism Treatment Network.

For more information about the 2014 events exclusively for families with children with autism at COSI, please visit Cosi.org.

April 10	6 p.m. to 9 p.m. (Education)
July 13	9 a.m. to noon (Arts & Sciences)
November 2	9 a.m. to noon (Assistive Technology)

To register for upcoming sessions go to:
<http://CosiAutismEvents.Eventbrite.com>

Patient and Family Centered Care Retreat Update

Paul Seese RN, MSN, Family Resource Center Coordinator

Patient and family centered care (PFCC) is an approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families and health care providers. It is founded on the understanding that the family plays a vital role in ensuring the health and well-being of patients of all ages. In PFCC, patients and families define their “family” and determine how they will participate in care and decision-making.

It is important that we frequently evaluate the culture of PFCC at Nationwide Children's (NCH). This past November, NCH invited a PFCC consultant to help lead a retreat on how to continue the progression of PFCC from philosophy to practice. Juliette Schlucter, president of Bridge Keeper has over 22 years of experience working with and leading health care professionals in PFCC assessment, programming design and implementation. She has

consulted on patient and family centered topics related to quality, safety, education, research and outcomes with numerous health care systems, national organizations and agencies.

Since 1996, Juliette has served as Faculty and Consultant to the Institute of Patient- and Family-Centered Care (IPFCC) speaking, leading workshops and developing action plans with health care leaders. A team of NCH staff and family leaders met Juliette at the IPFCC in April of 2013. It was decided then to invite Juliette to NCH to assist with developing an action plan to advance PFCC.



The first half of the day focused on ways to move PFCC from philosophy to practice. Juliette explained the importance of collaborating with family partners to enhance current PFCC initiatives. She discussed the importance of how to communicate our mission, vision and values to the community. Examples included sharing successes online, in publications, applications and social media. Juliette led the group in an exercise of prioritizing opportunities and barriers for NCH to move from philosophy to practice. Top priorities included aligning the family advisory group with the hospital strategic plan and effective communication. Top barriers included being consistent and creating a culture of cultivation.

At lunch, Juliette presented, “Shall We Dance? Partnerships to Advance Patient and Family Centered Care.” Juliette defined the core concepts of patient and family-centered care and the relationship to safety, quality and the experience of care. She stressed the importance of shared national best practices for advancing a culture of PFCC. Juliette eloquently illustrated multi-disciplinary roles for staff and family partnership, the shared perspectives and value in partnership. Juliette explained that best practices include engagement of families in clinical

rounds and change of shift report including being transparent with risks and safety measures.

At the end of the day, the group agreed to focus on aligning the work of the Family Advisory Council with the hospital strategic plan. Our action plan will include communicating the goals and successes of the Family Advisory Council through an online portal. Juliette recommended that we work on improved communications and increased awareness and visibility of PFCC initiatives via the intranet and internet. The intranet is vital for collaboration between hospital staff and other councils. It was identified as being important for the family councils to align with each other. Documentation of minutes from group meetings was seen as being key to sustaining a collaborative culture within the hospital. The hospital's PFCC team, a multidisciplinary committee, will take the lead in moving forward to address recommendations from the retreat.

The day long retreat helped bring the perspectives of patients and families directly into planning. This approach to planning is a journey, not a destination—one that requires continual exploration and evaluation of new ways to collaborate with patients, families and staff.

2013 Partners in Care, Partners in Hope Award

Allison Kingsley, FAC Past Chair, Selection Committee Chair



Each year Nationwide Children's Hospital hosts an employee recognition dinner. This year's banquet was ushered in with another snowy day coupled with cold temperatures and bad driving conditions.

Everyone's spirits were high despite the weather outside.

The award ceremony began with the announcement of the 2013 Partners in Care, Partners in Hope recipient. Linda Stoverock, chief nursing officer, has the annual honor of familiarizing the audience with the core concepts of family centered care and inviting the family that wrote the nomination onto the stage. Unfortunately, the adult patient that wrote the nomination was unable to attend due to Mother Nature. Linda revealed Omar Mohamud, a respiratory therapist in the pulmonary unit, was this year's recipient. Omar proudly accepted the award and followed with a brief humble speech after the nomination letter was read.

The nomination letter stated, "I have had a lot of respiratory therapists over my twenty five years of life and Omar has cared for me through some of the most traumatic medical situations of my life. When I needed to have a procedure done at an adult hospital, Omar stayed with me through the entire procedure, including the extremely painful recovery. I know that it may not seem like much to an outsider but it was terrifying to me to be in a place where no one knew me and he helped me feel comfortable and safe. Omar's ability to work with people he didn't know and ensure my safety at the same time was a huge deal to me." The entire nomination letter can be viewed on the hospital's website under Family Advisory Council.

The award itself is also a surprise. Each year a local artist creates a unique piece of artwork for the Partners in Care, Partners in Hope award. They are one of the few people that know the recipient before it is announced. They use the nomination letter to help find their vision for the award. This year's award was made by Rob Abel, a contemporary photographer and an award-winning videographer.

Coming soon: Dr. Noritz's Corner

In the future issues of *Family to Family*, Dr. Garey Noritz, 2013 physician of the year, will have a featured column to address common health issues people frequently ask him.

Who Are We?



My name is Julie J. Tunnell and I am the mother of three children, Kristine, Jordan and Jessica. My husband, Kurt, is an attorney at Bricker and Eckler.

I have a background in education with a B.A. in Elementary and Special Education, and a Master's degree in Gifted Education as well as a supervision certification. I taught elementary students for two years in Circleville, Ohio and then six years in Dublin City Schools. I also served as the coordinator for the gifted and talented programs in Dublin for four years before deciding to become a stay-at-home mom and part-time educational consultant. As a parent of twins, one with chronic medical issues related to a congenital diaphragmatic hernia (CDH), I have experienced a variety of medical departments and clinics at Nationwide Children's Hospital over the past 20 years. The list of services would include surgery, NICU, PICU, ECMO, orthopedics, neurosurgery, gastroenterology, immunology and pulmonary care.

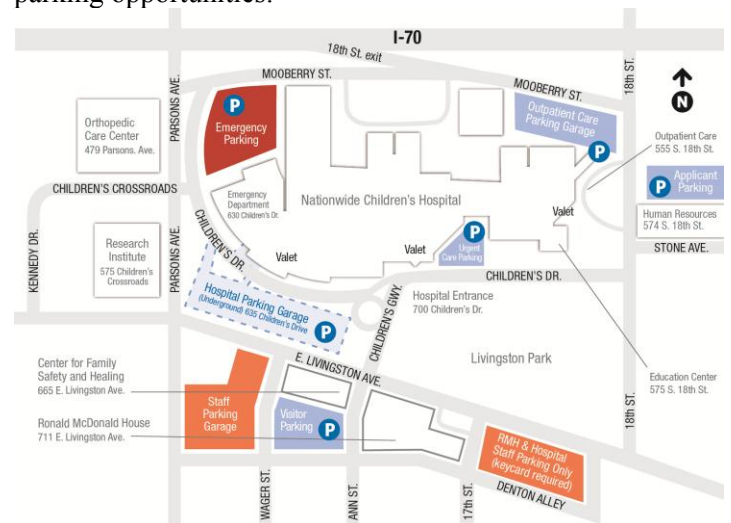
Once my children were older, I began to seek ways to connect with and help other parents with a similar diagnosis. I implemented a tote bag program for mothers who were to give birth to a CDH baby at Nationwide Children's Hospital. I connected with a staff member at the Ohio Fetal Medicine Collaborative at OhioFetalMedicine.org. After working with the collaborative for about two years, the staff member suggested that I consider being a member of the Family Advisory Council. At the time, my daughter was admitted to the hospital for a Nissan fundoplication surgery, and it was during this week long stay that I sought out the form to serve on the Family Advisory Council.

I have served on the council for two years and just began my second term. I have been participating in the education committee for two years and have enjoyed helping to select the Partner's In Care

Award winners, reviewing Helping Hands brochures for parents and going on family centered rounds among other projects. I am excited about the new opportunity to serve as chair of the education committee. I recently completed the training for Connecting Families and have a newly assigned mentee that I enjoy mentoring. Other volunteer opportunities include serving as the Ohio representative for CHERUBS, a national organization for parents of CDH children.

Parking

Recent changes on campus have resulted in new parking opportunities.



Above is a detailed map describing the parking options. You can also view this map by visiting NationwideChildrens.org/Hospital-Parking. On that webpage, take note of the section about handicap parking options, especially the information for those who drive high-top handicap vans.

Interested in more options for high-top van parking? Speak with Patient Relations by calling (614) 722-6593 for more information.

Coming to campus? Try these parking suggestions:

Outpatient Care Clinics – Outpatient Care Parking Garage (Mooberry St. and 18th Street)

Education Center – Outpatient Care Parking Garage (Mooberry St. and 18th Street)

Emergency Services - Emergency Dept. Parking Lot

Heart Center, Hematology/Oncology Unit, Surgery Center - Valet Parking or Hospital Parking Garage (Off Children's Drive, near Parsons Ave)