

Pediatric Patient and Family Advisory Council

Annual Report 2019

Members, 2019

Laura Spiegel, Chair

Toya Baker

Cherilyn Baney

Melody Brand

Kara Casavan

Chris Conner

Seema Dave

Sandy Davis

Brent Dikeman

Brittany Gummere

Carey Harris

Tara Harris

Sherry Kraft

Kim Mears

Holly Paauwe

Kristen Sharpe

Katie Vescelus

Roxanne Whitely-Anderson

New members who joined the council late in 2019 include Melody Brand and Tara Harris. Five members ended their terms at the close of 2019. Melody Holmes and Sara McWhorter will begin their terms in January 2020.

Riley Hospital for Children at IU Health leadership staff

Matt Cook, president

Paul Haut, MD, chief operating officer

Elaine Cox, MD, chief medical officer

Emily Webber, MD, chief medical information officer

Tracy Miller, director, Riley experience and design

Sara Barnett, manager, Child Life

Susan Schwarz, program manager, volunteer resources

Staff support for the council is provided by Darla Cohen, project manager, patient and family experience

Mission

Since 2009, the Pediatric Patient and Family Advisory Council (Pediatric PFAC) has been dedicated to promoting delivery of the highest standard of patient and family-centered care at Riley Hospital for Children at Indiana University Health. By strengthening partnerships between patients, families, healthcare providers and the community, the council works to advance a better healthcare experience for patients and families. While broad goals are set each year, additional improvement projects identified by staff or other families are also considered by the council. The feedback and guidance they provide results in a multitude of accomplishments, large and small, that make a tremendous difference for all.

Pediatric PFAC 2019 goals

- Align Pediatric PFAC work with Riley Hospital for Children at IU Health strategic initiatives so that the voice of the customer guides initiatives, programming and policy.
- Ensure that information shared with patients and families is meaningful, understandable and of value.
- Increase patient/family engagement and participation in quality improvement efforts to implement changes that positively impact patient experience delivery.
- Improve family engagement and participation in activities designed to achieve patient safety goals identified as priority for Riley at IU Health.

Presenters at 2019 meetings and corresponding topics

Nancy Swigonski (with Kara Casavan): strategic planning session to guide identification of goals aligned with the Riley at IU Health strategic plan

Susan Schwarz (on behalf of the Kiwanis): request for feedback on additional items for the parent comfort cart

Darla Cohen (on behalf of system experience design team): request for feedback on what matters most to families and how to make it easy

Darla Cohen (on behalf of USP 800 work group): feedback on patient/family education sheets and signage related to the new hazardous drug regulations and procedures



Riley Children's Health
Indiana University Health

Presenters at 2019 meetings and corresponding topics (continued)

Tracy Miller: quarterly patient experience updates including real-time feedback net promoter scores and comments providing insight into areas in need of improvement; requested feedback on issues identified in real-time feedback comments

Johann Chikkala: request for parent participation in select transformation activities requiring the voice of the customer perspective

Doug Starr: requesting feedback on barriers to parent participation in transformation activity in general

Tracy Miller: request for council members to collect data in advance of guest management implementation

Joe Anderson: request for feedback on the Riley guest management system implementation

Cindy Latty: requesting feedback on the essential content for the Riley Welcome video for new patients and families

Shelly Cates (from the Ronald McDonald House): update on leadership changes at the house and confirmation that parent feedback previously submitted was being addressed with changes in procedure

Deb Kilpatrick: requesting feedback on logistics of Cipher discharge calls to families

Sandy Davis and **Roxanne Whitley-Anderson:** reported on their participation in the Parking Task Force “tabletop” exercise to plan and implement a more efficient method of parking for Riley patients and staff

Emily Webber, MD: update on new additions to the electronic medical record including Know Me and Camera Capture, which allow more details about the patient preferences to be included in the chart as well as a photo; she also described a new scheduling feature

Laura Spiegel: presented on her new blog “Paint Her in Color”

Chris Fogle: update on the Navigate Riley app and a bereavement app currently under development

Kim Mears: update on the Emergency Medicine Services for Children conference she attended

2019 highlights

The Pediatric PFAC contributed to over 36 concrete changes to improve the healthcare experience at Riley and throughout IU Health.

Navigate Riley: Since its implementation on Nov. 4, 2019, 640 users have accessed the tool. The first week saw heavy usage (which is typical with a launch). That has leveled off to about 25 users per day with more than 500 routes taken in the first two months of usage.

Safety Advocate collaboration: Riley Safety Advocates and Family Advisors co-sponsored three information tables in the Riley at IU Health Simon Family Tower to promote family participation in error prevention techniques.

Patient portal correction: A council member recognized notifications of secure messages sent on the IU Health patient portal had stopped, informed Clinical Informatics and the issue was investigated. Approximately 2,000 patients were affected, and the problem is now solved.

Strategic plan for council: Four council workgroups were formed to develop plans to address the broad topical areas of improving emotional support for patients/families in isolation, increasing awareness of existing resources in the hospital for patients and families, broadening the diversity of the council and improving overall awareness of the council and its purpose through serving hospital staff.

Council members highlights

Members of the Pediatric PFAC are often called upon, or volunteer, to assist with other efforts throughout the hospital to improve the experience for both patients and staff. Some examples of these additional Riley-related efforts are:

- Filmed two Riley Children’s Health videos for Facebook
- Participated in Riley Children’s Health article on PTSD in parents
- Served as VIP assisting families visiting Riley
- Presented multiple times to students in the IU School of Nursing Collaborative Practice class
- Volunteered to do voice-over in Oncology video describing experience



Council members highlights, continued

- Identified five issues during personal visits to Riley resulting in improved processes or corrections to unacceptable environmental situations
- Assisted with Riley pilot test of national tool to assess family engagement sponsored by Family Voices
- Led shaping of 2019 Pediatric PFAC areas of focus
- Assisted in hosting staff visitors from West Central Region patient experience
- Served on the Parking Task Force to redesign parking procedures at Riley Hospital for Children at IU Health in downtown Indianapolis
- Visited Dayton Children's Hospital for patient experience ideas
- Donated balloons multiple times a year to Riley patients in the PICU through Carter's Balloon Project
- Served food to staff on Riley Employee Appreciation Day
- Interviewed for Children's Miracle Network live broadcast about "gaming for extra life" fundraising for Riley
- Served as Riley Cystic Fibrosis (CF) Family Advisory Board member with following responsibilities
 - Authored quarterly family newsletters for the CF clinic
 - Contributed to Newly Diagnosed Family binder for CF clinic
 - Cystic Fibrosis Foundation parent mentor
 - Cystic Fibrosis Foundation fundraising parent storyteller
 - Cystic Fibrosis Lifestyle Foundation Board of Directors
 - Cystic Fibrosis Lifestyle Foundation 5-year strategic plan lead
 - Cystic Fibrosis Lifestyle Foundation blogger
- Represented Riley at Senior LPGA in French Lick, Indiana
- Assisted with development of survey for Sibling Care proposal
- Led effort to improve experience for children in isolation at Riley

Thank you for asking me to be part of this [council]. I am proud of the work that is done, and what will continue to be accomplished. It is so full circle for me as a mom of a Riley kid.

Sandy Davis, council member and Riley parent

Some Pediatric PFAC members serve on other councils, boards or committees and/or volunteer their time to support efforts not directly related to Riley Children's Health. Select examples are:

- Published article on The Mighty digital health community
- Published article on the CF Warrior Project
- Published blog A Life of Rarity
- Percentage of family business profit donated to pediatric cancer research (\$1,542 in 2019)
- Launched Paint Her in Color website to offer emotional support to parents of children with special healthcare needs
- Secured partnerships with Family Voices, About Special Kids, HANDS in Autism, Health Advocacy Summit, Healthy Heart Families, the Cystic Fibrosis Lifestyle Foundation and The CF Warrior Project for inclusion on the Paint Her in Color website
- Facilitated implementation of Random Acts of Flowers (RAF) at IU Health North and Saxony hospitals
- Serves as lead volunteer for RAF at IU Health North Hospital and St. Vincent Hospital
- Serves as weekly cuddler in the NICU at IU Health North Hospital
- Volunteers at IU Health North Hospital for Project Sunshine as well as at Peyton Manning Children's Hospital
- Serves on the IU Health system level Patient and Family Advisory Council
- Facilitates deliveries of food from Einstein Bagels to Ronald McDonald House as needed
- Serves on the Emergency Medicine Services for Children National Family Advisory Board
- Volunteers for No One Dies Alone
- Manages annual Cooper's Troopers fundraiser for pediatric cancer research (total nearly \$5,000 in 2019)
- Submitted application to attend the Patient Centered Outcomes Research Institute (PCORI) sponsored Parent/Patient Advisor Summit and was accepted to represent Riley at that event in Washington, D.C.
- Facilitated attendance of Pediatric Residents during their Community Pediatric Rotation in their Developmental Behavioral Pediatrics and Child Development elective



2019 Members insights about being a family advisor

Kara Casavan

What brought you to Riley: Our son Cooper spent the majority of his six years as a patient of Riley and benefited from the care of numerous specialty teams and hospital staff. I have served as family faculty and on the Pediatric PFAC. Because of my roles, I have been honored to speak on behalf of Riley and continue to work with nurses, medical students and physicians regarding family-centered care.

2019 accomplishment most proud of: The amount of family/parent provided input that was used in decision making within Riley. I love seeing families witness their contribution improving care for others.

Holly Paauwe

What brought you to Riley: I'm the parent of two children, one with multiple disabilities and complex special healthcare needs who has received care at Riley Hospital for Children for all of her almost 15 years. Because of her rare diagnosis and complexity, she's also received care within other regional and out-of-state healthcare systems.

As a council member, I have the opportunity to share personal patient-family perspectives on how Riley can continue to reflect on and improve on its promise of delivering patient- and family-centered care, while also being a crucial voice at the table representing the larger community of patient-families receiving care there. I came to this role as not only a parent of a child with complex needs who received care at Riley, but as an experienced parent-to-parent professional and advocate who was also greatly influenced and informed by the countless families—from all backgrounds raising kids with a variety of chronic and acute health needs—I'd had the great privilege to work with over the years. The collective experiences of those families routinely influenced my council contributions as much as, if not more than, my own family's experiences.

Additionally, as a patient-family with varied pediatric healthcare experiences within other major health systems, I have the ability to contribute perspectives from an "outsider" or "competitor-like" lens that I really believe brings added value to any improvement work.

Professionally, since the birth of my daughter at least, I have worked in the parent-to-parent field supporting and empowering families raising children with special needs, in the medical field serving families of children with autism or developmental disability as a clinic-based, family-leader care coordinator, and most recently as a rotation coordinator within an academic pediatric residency education program.

For the last 12 years, I've also had the great honor of running a web-based support network for families raising children with the same primary diagnosis as my daughter. Through all these roles, my primary goal has been to make sure families feel connected, valued, empowered and heard.

As the ultimate consumers and experiencers of healthcare that our children and families are, we must have a meaningful and transformative voice at the table of the systems and programs that provide care. I'm grateful that PFAC has provided and will continue to provide one of those tables for patients and families at Riley.

2019 accomplishment most proud of: Serving on the Steering Committee for the Riley Guest Management System, which provided a platform to strengthen and improve design and implementation planning from the critical patient and family perspective.

Cindy and I really enjoyed being part of the PFAC meeting last evening. Every single person at that table had quite remarkable contributions and insight into the care of children and their parents. What a wonderful group you lead. We will certainly take into consideration the comments offered by the members and really appreciate their time and sincere attention.

Debra Kilpatrick, MSN, CPNP, RN-BC



2019 Members insights about being a family advisor, continued

Tara Harris

What brought you to Riley: My daughter was born with multiple health issues, one of those being a congenital heart defect. She had open heart surgery at Riley at 4 months old, and her entire cardiovascular team was wonderful. She sees multiple doctors and therapists at Riley, and we couldn't be happier with the care she's received. As a Riley Family Advisor Volunteer, it is my job to make sure the needs of family members are heard. That can mean giving input on how to make hospital stays less intimidating, or even as small as how to better navigate Riley while you're there.

2019 accomplishment most proud of: Being involved with the Navigate Riley app.

Sandy Davis

What brought you to Riley: Our youngest son, Cooper, was diagnosed with Philadelphia chromosome positive B-cell acute lymphoblastic leukemia in July of 2015 when he was 11 years old. I have a few different roles at Riley. I am a board member of the Pediatric Patient and Family Advisory Council, or PFAC. I volunteer as a VIP, helping patients, families and visitors navigate their way around Riley and seeing to it that they arrive at their intended destinations. I am also preparing to help with establishing a parent mentor program in the Oncology department, where we will connect families to other families, who have "walked in their shoes" and are willing to guide them along their journey.

2019 accomplishment most proud of: The accomplishment I am most proud of for 2019 was the input I was able to provide at the Riley Parking Task Force meetings. Due to our own personal inpatient and outpatient experiences at Riley, the information I was able to share turned out to be very helpful when it came to some of their decision making.

As always, the council members outdid themselves in 2019 taking on new challenges, at the local and national levels. While supporting Riley families and each other, they also supported and inspired me.

Darla Cohen, project manager, patient and family experience

Brittany Gummere

What brought you to Riley: My daughter has two rare genetic diseases and requires care from many specialists at Riley. Professionally, I am a NICU Nest Family Support Coordinator at IU Health Methodist Hospital and the SFT 9E Progressive Care Nursery. As a member of the PFAC and as Family Faculty, I work with Darla Cohen and other Riley families educating nurses, residents and other providers on how best to provide family-centered care.

2019 accomplishment most proud of: Speaking to residents and nursing students about my daughter's journey and realizing the power her story holds.

Kim Mears

What brought you to Riley: I'm a mom to two boys—Jackson, 25, and Carter, 14. Carter was my Riley child—he was diagnosed with Crohn's disease at 2 years old, then pediatric neuro Behcets's disease at 8 years old. He was treated and followed by a large number of specialists, and after a long battle spent mostly in the ICU, Carter was diagnosed by the NIH with A-20 NEMO deficiency in August 2015. Sadly on Oct. 17, 2015, at age 9, Carter passed away at Riley surrounded by lots of family, friends and staff.

I have had the pleasure of being on the PFAC since January 2016. I have had the honor of speaking at new nurse orientation and to advanced classes of nursing students. I have participated in six LEAN activities—probably some of my favorite weeks spent back at Riley. It's amazing to be able to work and solve problems with the same people that have helped our family so many times when Carter was hospitalized. I am the fan advocate for the IN EMSC and have traveled to two conferences and met some of the biggest family advocates. I was a fan advocate in 2018 for SAEM and along with three other family advocates, we were the first non-medical people to ever speak at the medical conference. I also volunteer for No One Dies Alone (NODA), a blessing to be able to give back to someone that has no one during their final hours. This is my fifth year on the Riley Pediatric Critical Care Walkathon. I am continuing Carter's wish by running the Carter's Balloon Project—we drop off balloons to Simon Family Tower 7 West and both ICU floors 6 – 8 times a year.

2019 accomplishment most proud of: I'm the proudest of being able to use the knowledge and experience from being a Riley mom to give back and help other parents navigate being in the hospital and how to manage their new normal.



Roxanne Whitley-Anderson

What brought you to Riley: In July 2017 my grandson, Jaicion “Paco” Myles, was diagnosed with Stage 4 neuroblastoma and we spent about 17 months, more in than out, at Riley Hospital for Children and thankful to God, we live with several success stories for our little guy. After being exposed to Riley a few months, I would tell my family I have to find a way to give back. We became family with the Riley team and many of the Riley families. The doctors, nurses and volunteers worked so diligently with my daughter and my family during my grandson’s in-patient stays and his ongoing appointments. I reached out to a couple of groups connected with Riley, but when I met Darla, I knew I had connected with the right person. Darla introduces me to Susan and it’s no turning back now. I became a volunteer with Riley Hospital in 2018 in the role of VIP Experience, and in 2019 I earned the privilege of taking the VIP Experience role deeper. Once a week I would meet with maternal fetal families and personally escort them to their appointment between Riley and IU. As a Riley grandma this role blesses me because I remember trying to navigate through the halls and elevators to get to where we needed to be.

2019 accomplishment most proud of: Being able to serve others so they have an easier path.

Laura Spiegel

What brought you to Riley: My daughter has received cystic fibrosis treatment at Riley since she was five weeks old. I am the parent chair of the Pediatric PFAC at Riley. I partner with Darla Cohen to develop the council’s strategic priorities and facilitate monthly dialogue regarding the experience of care for Riley families. I worked in healthcare for 12 years before becoming a full-time writer and health advocate. In 2019, I founded Paint Her in Color, a website that offers emotional support to parents of children with special healthcare needs. I also served on the Family Advisory Board for Riley’s Cystic Fibrosis Center; the Board of Directors for the Cystic Fibrosis Lifestyle Foundation; and as a regular blog contributor to a number of parenting websites.

2019 accomplishment most proud of: I am most proud of helping to identify and elevate a glitch in the “My IU Health portal” that was causing barriers to timely patient/provider communication.

Sherri Kraft

What brought you to Riley: I have two adult daughters, and my youngest has multiple complex health conditions. She was a Riley Kid as a child, and has doctors throughout the IU Health system and other hospital systems across the U.S. I am extremely passionate about giving back to the healthcare system that has helped my child so much over the years. I am an avid volunteer: I work with Project Sunshine to help bring enjoyment to pediatric patients, I am a “cuddler” in the NICU and I facilitated a partnership with Random Acts of Flowers at two IU Health hospitals. I also work to share my experiences in hopes of helping the next generation of patients and families as a member of the Riley PFAC.

2019 accomplishment most proud of: The implementation of the additional security measures now in place at Riley Hospital.

Katie Vescelus

What brought you to Riley: My son, Matthias, was diagnosed at Riley with bilateral retinoblastoma (cancer of both eyes) in December 2008. He has been a Riley patient his whole life, and I want to use our experiences to help other families. I have been a member of PFAC since January 2019. I am a cancer mom, a mother of a child with a disability, a licensed social worker, and a certified trauma professional with particular interest in improving the psychosocial supports available for families facing serious illness. I endeavor to bring my education and experience to all PFAC projects.

2019 accomplishment most proud of: I am proud to participate in my first year as a PFAC member in 2019, and I look forward to contributing more in years to come.

This is FABULOUS feedback. I very much appreciate you presenting this and will add it to the compilation we are creating. Thank you so much and have a great remainder of your week.

Julie R. Ruschhaupt, MSN, RN, BS, ACC-ICF
System Director – Experience Design Application



Chris Conner

What brought you to Riley: My daughter was born in 2016 with hypoplastic left heart syndrome. She has undergone three open heart surgeries and had a G-tube. I became involved in PFAC after I volunteered to serve as a mentor to other families with children with congenital heart defects. I have helped to problem solve some of the issues identified within Riley by PFAC, to include concerns over long lines at the security checkpoints.

2019 accomplishment most proud of: Being a mentor for another cardiac family.

Toya Baker

What brought you to Riley: I'm the parent of two children with chronic health conditions and both receive care at Riley. In addition to serving on the PFAC, I am a parent mentor for the GI Clinic at Riley. I volunteer at the Crohn's and Colitis Foundation.

2019 accomplishment most proud of: Team Advisor and Planning Committee Member for Take Steps, which is the annual fundraiser and celebration for The Crohn's and Colitis Foundation – Indiana Chapter.

Carey Harris

What brought you to Riley: I am the parent of three children whom receive care at Riley. Two of my children have cystic fibrosis and are seen in multiple centers, they have both been inpatient on several occasions. My other child is a patient in the Endocrinology Center. I am actively involved with the PFAC and Cystic Fibrosis Family Advisory Board

2019 accomplishment most proud of: Approval for the battery powered color and shape projectors for patient rooms. Completing coursework through the Beryl Institute in preparation for the CPXP exam.

The feedback we received from the council gave us insight to the needs and wants of families who come to Riley. This is invaluable since we are creating something that will be utilized by those families. We want to develop something that will be beneficial to them.

Maureen Battles
Patient Education Coordinator, Pediatrics
Nursing and Patient Education
Riley Hospital for Children at Indiana University Health

Melody Brand

What brought you to Riley: My middle daughter, Lucy, was born with several heart defects. She has received wonderful care at Riley for the six years of her life. I'm a member of the PFAC and volunteer where I am needed.

2019 accomplishment most proud of: I volunteered to help the new Maternal Fetal Medicine department with their practice run-throughs before they opened for the first time. As a former maternal fetal medicine patient at a different hospital, I am passionate about helping improve the experiences for future moms at Riley. I'm also proud that my family and friends come together every year to support the Ronald McDonald House at their Heroes for the House 5k. For the past six races we have had either the biggest team or the team with the most money raised.

Cherilyn Baney

What brought you to Riley: I'm the parent of two girls with hypermobile Ehler's Danlos syndrome (hEDS). My older daughter has been afflicted the most by this syndrome. She spent a lot of time seeing Riley doctors throughout her childhood then ended up there for a week about two years ago to receive a feeding tube. My younger daughter has been fortunate enough to be doing well so far. But I know she would be in good hands if need be. I, myself, spent time off and on as a child at Riley for my hearing loss.

My role with Riley involves being on the PFAC. I joined hearing about it after my daughter was at Riley for the one-week stay. I'm a natural problem solver and felt I would be an asset to the council. I have given many ideas and have had a couple of ideas come to fruition. I continue serving on this council knowing how much any one of us can make a difference for the patients, families and healthcare professionals at Riley.

2019 accomplishment most proud of: Making sure all hearing impaired/deaf families and patients are able to purchase batteries for their hearing aids/cochlear implants right inside Riley's facilities so they can get back to their child to hear important information being given by the doctors or the children can continue to play, listen and learn without much loss of time.

