

Pediatric Patient and Family Advisory Council

Annual Report 2020

Members, 2020

Laura Spiegel, Chair
Cherilyn Baney
Melody Brand
Christine Chambers
Sandy Davis
Jennifer Demotte
Carey Harris
Tara Harris
Sherri Kraft
Sarah McWhorter

Kim Mears
Darleata Mitchell
Beth Walsh
Roxanne Whitely Anderson
Katie Vescelus

New members joining the council in 2020 include Beth Walsh, Darleata Mitchell, Jennifer Demotte and Christine Chambers. Kim Mears and Sherri Kraft ended their terms this year, and Laura Spiegel completed her second and final year as Council Chair, having led the group successfully toward completion of their goals. Carey Harris will assume Council Chair responsibility for 2021.

Riley Hospital for Children at IU Health Leadership Staff

Matt Cook, President
Paul Haut, Chief Operating Officer
Elaine Cox, Chief Medical Officer
Emily Webber, Chief Medical Information Officer
Tracy Miller, Director Riley Patient 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

A Word About 2020

As the year began, the world was a different place than it is now. Like most in the healthcare community, Riley staff and families were hopeful, encouraged and eager to continue making a difference through improvements to the patient and family experience. Within two months, that all changed as a deadly coronavirus spread across the globe. The virus was called many things in the beginning of its spread, but eventually COVID-19 became part of our everyday language. It affected every aspect of our lives. There is no denying the negative consequences and unspeakable tragedy that resulted in every corner of this earth. Yet there were some positive moments. At Riley, some of those moments were due in part to the commitment of the families serving on the Pediatric Patient and Family Advisory Council (Pediatric PFAC). They are to be commended for their continuing dedication in the face of this year's global pandemic. The results of their work will be felt far into the future, long after COVID-19 fades. For this, we are all grateful.

MISSION

To promote the delivery of the highest standard of patient and family centered care at Riley Hospital for Children at Indiana University Health.

The Council works to advance a better healthcare experience for patients and families by strengthening partnerships between patients, families, healthcare providers and the community. The Council goals that are set annually align with both the Riley Children's Health and IU Health strategic plans. In addition to those broad goals, the Council considers proposals and improvement projects identified by staff and/or families. The feedback and guidance they provide influences decisions made regarding the hospital's policies, programs and procedures. The resulting continuous improvement accomplishments, large and small, make a tremendous difference for all.



Riley Children's Health
Indiana University Health

Pediatric PFAC 2020 Goals

- Improve the emotional experience of inpatient families especially those in isolation
- Increase cultural, language and socioeconomic diversity of PFAC representation
- Improve inpatient family awareness of and access to available support resources within the hospital

The Pediatric PFAC contributed to **over 30** concrete changes to improve the healthcare experience at Riley and throughout IU Health. Some of these were directly related to the hospital's response to the COVID-19 pandemic and others were part of planned activities designed to improve the overall patient/family experience. In addition, council members continued to donate their time and energy to professional development activities, disease specific events and foundations, representing Riley Children's Health at a state and national level and responding to surveys and requests for feedback. Their engagement in all these opportunities is a testament to their commitment to ensuring the Riley patient and family experience is the best it can be.

2020 Meeting Presenters and Corresponding Topics

Jennie Gilmour – Request for feedback on the VEEG communication proposed for families

HANDS in Autism – Information on the role of the organization and upcoming events for families

Rebecca Kimball from Revenue Cycle – Request for feedback on educating families about billing options

Tracy Miller and Jeannette Champion – Request for participation in the Multidisciplinary Clinic improvement project

Tracy Miller – Request for feedback on improving the traffic flow of the Riley Outpatient Center lobby

Tracy Miller, Katie Flamion, Dr. Emily Webber, Josh Essingler – Request for feedback on the digital experience for families

Darla Cohen and Paul Haut – Request for feedback on name of newly remodeled Riley cafeteria

Tracy Miller – Request for feedback on updating signage throughout the hospital

Tracy Miller – Present information and request member participation in review of SONIFI product (part of digital experience improvements)

Adam Karcz and Kevi Harping, Infection Prevention Team – Request for feedback on proposal to use CHG soap rather than CHG wipes and to encourage bathing of patients

Tiffany Davis, Sara Erotas, and Carly Brandon, Emergency Department – Request feedback on next steps following Riley joining the Trauma Network and a proposed educational “flip book” for families

Michelle Curtain, MD – Request for family participation in physician education simulation to improve communication between families and providers

Melody Holmes and Katie Vescelus – Update on their participation in the Multidisciplinary Clinic improvement project

Darla Cohen – Information on 2020 goals revisions resulting from shifts in priorities due to pandemic

Adam Karcz and Infection Prevention team – Request for feedback on how to communicate to families the need for enhanced cleaning (and decluttering) of patient rooms

Maureen Battles, Tanya Couvillion and Jenna Yarnell – Request for feedback on CVAD (Central Venous Access Device) safety

Tracy Miller – Patient Experience update

Sara Barnett and Darla Cohen – Update on the “What Matters Most” initiative

Tiffany Davis and Sara Erotas, Emergency Department – Request for feedback on the Trauma flip book

Darla Cohen (on behalf of Oncology team) – Request for feedback on the “Distress Thermometer” and corresponding pilot study

Jacob Taylor – Presented demonstration of the completed bereavement app developed for Riley and IU Health, which is also available nationally

Darla Cohen – Request for feedback on “What does good look like when a physician leaves Riley?”

Joe Anderson – Update on decisions related to the Parking initiative

Jordan Huskins, MD – Request for family participants in quality improvement project focusing on families whose children have autism

Dena Vincent – Update on new Indianapolis Public Library collaboration with Riley Hospital Block Family Library

Adam Karcz, Infection Control – Request for feedback on how best to communicate mask mandate in patient rooms



2020 Council Highlights

PCORI SUMMIT

Council member Sandy Davis was selected to attend the national Patient Centered Outcomes Research Institute (PCORI) Parent/Patient Advisor Summit. She described her experience representing Riley at that event in Washington, D.C. as “amazing.” In her report to the Pediatric PFAC following the summit, Sandy said one of her strongest impressions was that the Riley Family Advisor program is fully supported in many ways while other advisory programs across the country are not. Another was how much more advanced Riley is in terms of the value placed on advisors as evidenced in their inclusion in a wide variety of improvement projects and in decision making. Sandy mentioned how motivated she was upon her return and looked forward to continuing her participation in all quality improvement efforts at Riley. She was grateful for the mentoring received and encouragement to “stretch” to accomplish more than she ever knew possible.

“The support you give us is not the norm. Until you go somewhere like this, and see how great you are, you have no idea it’s not like that everywhere. I was glued to the speakers. I was a sponge. It was so awesome. I walked away finding my purpose and I’m laser focused on what to do.”

[Sandy Davis]

NAVIGATE RILEY 2.0

The second iteration of the Navigate Riley app was completed with addition of additional landmarks on the first floor of the hospital including the blue, green and orange elevators. Families continued to use this tool to assist them with wayfinding. The third edition will be developed in 2021 adding in several of the amenities located throughout the first floor including the new Riley Maternity Tower, the Ronald McDonald House, eateries and ATMs.

PARKING TASK FORCE

Moving into its second year, the work of the Parking Task Force continued with Sandy Davis and Roxanne Whitley Anderson representing the family voice. After lengthy negotiations and planning, the recommendation of the task force was achieved: Patients and families would be directed to park at the entrance nearest their appointments. As an additional bonus, there will be no difference in price for outpatient visits whether families park at the ROC or SFT and inpatient families will park in the SFT garage at no charge.

VISITOR RESTRICTION MODIFICATIONS

With the implementation of the strictest visitor restrictions ever imposed at Riley, the Council, together with other families’ feedback, successfully lobbied to modify the “one parent per child” restriction so that two parents could be present together on the day of surgery. Additionally, restrictions were amended to allow parents to “switch places” at earlier intervals than initially proposed.

IN-ROOM PATIENT LIGHT/SOUND MACHINES

Council members with a specific interest in improving emotional support for patients/families in isolation continued to work on ideas to achieve this goal. One popular idea was to purchase light/sound machines for patient rooms that could be controlled by the patient (or family) to provide some distraction for long hours spent in the patient room. This became much more important during the pandemic as families were asked to restrict their movement throughout the hospital thus lengthening the actual time spent in the patient room. The funding for the machines was approved, and the equipment will be installed for trial in the first quarter of 2021.

HYGIENE STATIONS

New infection prevention protocols were initiated by IU Health, requiring all visitors to wear hospital-provided masks upon entry to the facility. While supporting this initiative, council members felt there could be significant improvement in the method of distribution. Effective input and lobbying spearheaded the acquisition of visually-appealing freestanding stations for each lobby that efficiently and hygienically dispense masks and hand sanitizer for our patients and families.



FOOD

At various times over the past 4 years, nutrition, food options, menu choices, food prices and access to food has been discussed by the Council with no significant progress. In early 2020 while the cafeteria was still closed for remodeling, the other food vendors within the hospital reduced hours due to COVID-19 and the Ronald McDonald House within the hospital closed. Families were very restricted in the options available for them to eat. At the suggestion of the Council, Riley leadership agreed to provide in-room meals to the parent with the patient at no cost. This was a huge win both

for the families who were guaranteed meals without having to leave the room and for the hospital because it minimized traffic throughout the hospital saving on PPE and minimizing the spread of infection.

As that benefit was phased out, families were encouraged to increase their use of in-room ordering. The advantage was the ability to pay by credit card in the room when the food was delivered without having to go downstairs to purchase food or food vouchers. Ongoing barriers are lack of awareness that the option exists, lack of credit cards and misinformation from staff about whether the option

exists at all. The cafeteria is now open which improves the options available to families. The high prices at all the hospital food vendors is still an issue the Council hopes to address in the future.

A food pantry was set up in the now closed in-hospital Ronald McDonald House, for staff use only. Thanks to suggestions from staff in the Emergency Department, bags of food are now prepared and distributed to families who present to the Emergency Department with food insecurity. The process is simple, bypassing much of the red tape usually associated with assistance programs.



TREASURED PFAC LEADER RETIRES

When Darla Cohen first joined Riley Hospital for Children thirteen years ago, then-CEO Dr. Ora Pescovitz advised her to make herself “indispensable.” As any past or present council member would agree, she took those words to heart. Darla’s advocacy for parents needing support during their child’s healthcare journey and commitment to practicing the principles of family-centered care guided her work at Riley Hospital and changed the lives of countless patients and families.

Drawing on her years of experience working with Indiana University in Bloomington, IU School of Medicine, and her own personal journey as the parent of a NICU infant with subsequent medical challenges, Darla succeeded in launching the first PFAC within IU Health – and Riley families had a voice. Under her leadership, Darla provided the support and encouragement for council members to become leaders, to affect change, and to make Riley better. She has often shared that the lived experiences of our families “are something we can’t buy as a hospital system. They are invaluable to us. They are the ones who give you the information you need to be better. All we have to do is act on it.”

“I think it's rare to find somebody who understands the ins and outs of the hospital from an operational perspective and a strategic perspective but who also is able to maintain the compassion and the empathy and the authenticity that she does. She gets it, and she doesn't give up. The fact that she went through the experiences she did with her own daughter gives her that perspective. I have witnessed so many times when she was able to comfort someone under immense stress just with her words.”

[Laura Spiegel]

“She helped us bring Dr. Morris Green's philosophy of family-centered care to life, from the Patient and Family Advisory Council to Family as Faculty to helping lead through our Guest Management initiatives. It's hard to imagine Riley Hospital without Cohen walking the halls, that is until you begin to think about the lasting positive impact she has had.”

[Paul Haut, MD]

“Darla's empathy, insight and enormous heart have inspired and motivated every one of us. We join Dr. Haut in saying we 'will miss Darla being a part of our daily life' and are 'confident her presence will continue to be known' at Riley Hospital for Children.”

[Susan Schwarz,
Program Manager
Riley Volunteer Resources]



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. In 2020, the pandemic drastically reduced in-person volunteering; however, the council members still contributed in a variety of very meaningful ways. Some examples of these additional Riley-related efforts are:

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| <ul style="list-style-type: none">■ Participated in the Day in the Life exercise to open the Maternal Fetal Center■ Presented poster at the Children's Hospital of Philadelphia Pediatric Cardiology conference in Orlando, Fla. on effective coping mechanisms parents use to reduce stress■ Participated in a focus group exercise, related to flow and security in the Riley Maternity Tower■ Presented to residents in their Community Health pediatric rotation■ Identified issues during personal visits to Riley and provided suggestions to alleviate those issues | <ul style="list-style-type: none">■ Advocated for push plates to be installed in the MSA clinic area so families could more easily access clinic area■ Co-designed and presented webinar for the Beryl Institute on Riley's Heart Center parent to parent mentor program■ Served on the Parking Task Force to redesign parking procedures on the Riley campus■ Served 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 | <ul style="list-style-type: none">■ Served as Riley CF Family Advisory Board member■ Authored quarterly family newsletters for the CF clinic■ Volunteered for the Volunteer Impact Program providing wayfinding and emotional support for anxious patients and families navigating the corridors of Riley■ Encouraged Zone to Go which provided 3,351 visits and was operating three to four days weekly by the 4th quarter with 950 visits■ Provided over 500 hours of volunteer service for Riley Hospital for Children |
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Some 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:

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| <ul style="list-style-type: none">■ Published articles on <i>The Mighty</i>, <i>Kevin MD</i>, <i>Complex Child Magazine</i>, and <i>Passionate World Talk Radio</i>■ Published article on the CF Warrior Project■ Published blog A Life of Rarity■ Donated percentage of family business profit to pediatric cancer research■ Facilitated implementation of Random Acts of Flowers (RAF) at IU Health North and IU Health Saxony hospitals■ Served 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■ Facilitates deliveries of food from Einstein Bagels to Ronald McDonald House as needed | <ul style="list-style-type: none">■ 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 this year)■ Facilitated attendance of Pediatric Residents during their Community Pediatric Rotation in their Developmental Behavioral Pediatrics and Child Development elective■ Cystic Fibrosis Foundation parent mentor■ Cystic Fibrosis Foundation fundraising parent storyteller■ Cystic Fibrosis Lifestyle Foundation Board of Directors, Board President■ Cystic Fibrosis Lifestyle Foundation blogger■ Contributing writer at <i>Special Needs Living Indianapolis Magazine</i> and <i>Different Dream Living</i> |
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