

2023 PATIENT & FAMILY EXPERIENCE PARTNERS ANNUAL REPORT



CARING *by*
Sharing

INTRODUCTION

It was a year of firsts for the Patient and Family Experience Partners (PFEP). A new council was launched devoted to AdventHealth for Women, and all the councils worked together with a goal of supporting patients and families both in the hospital and using outpatient services.

The longtime desire to provide a mentoring program at AdventHealth for Children also became a reality with the training of a first group of parents for the NICU Council who are ready to be paired with those seeking assistance with coping and navigating life with a newborn.

The AdventHealth for Children Family Resource Center expanded its footprint at the hospital with an additional hospitality cart permanently stationed in the NICU. Operating hours of the center also expanded to cover more nights and weekends.

Readers will notice the ongoing theme of the councils' desire to care for the community through service projects. Sit back and enjoy the many accomplishments seen in 2023.



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PHILOSOPHY & VISION

Each member of the PFEP has the ability to understand the real-life experience in our hospital and outpatient clinics. Either as a patient or a parent, they have seen what makes our system work and where improvements can be made to make things better for those who will utilize our services in the future. They understand the principles of family-centered care:

- Treating all patients and families with **dignity and respect**.
- Understanding the importance of **sharing information** and communication.
- Creating a **partnership** by understanding patients and families are a critical part of the care team.
- **Collaborating** with patients and families beyond their personal hospital experience to make improvements for everyone.

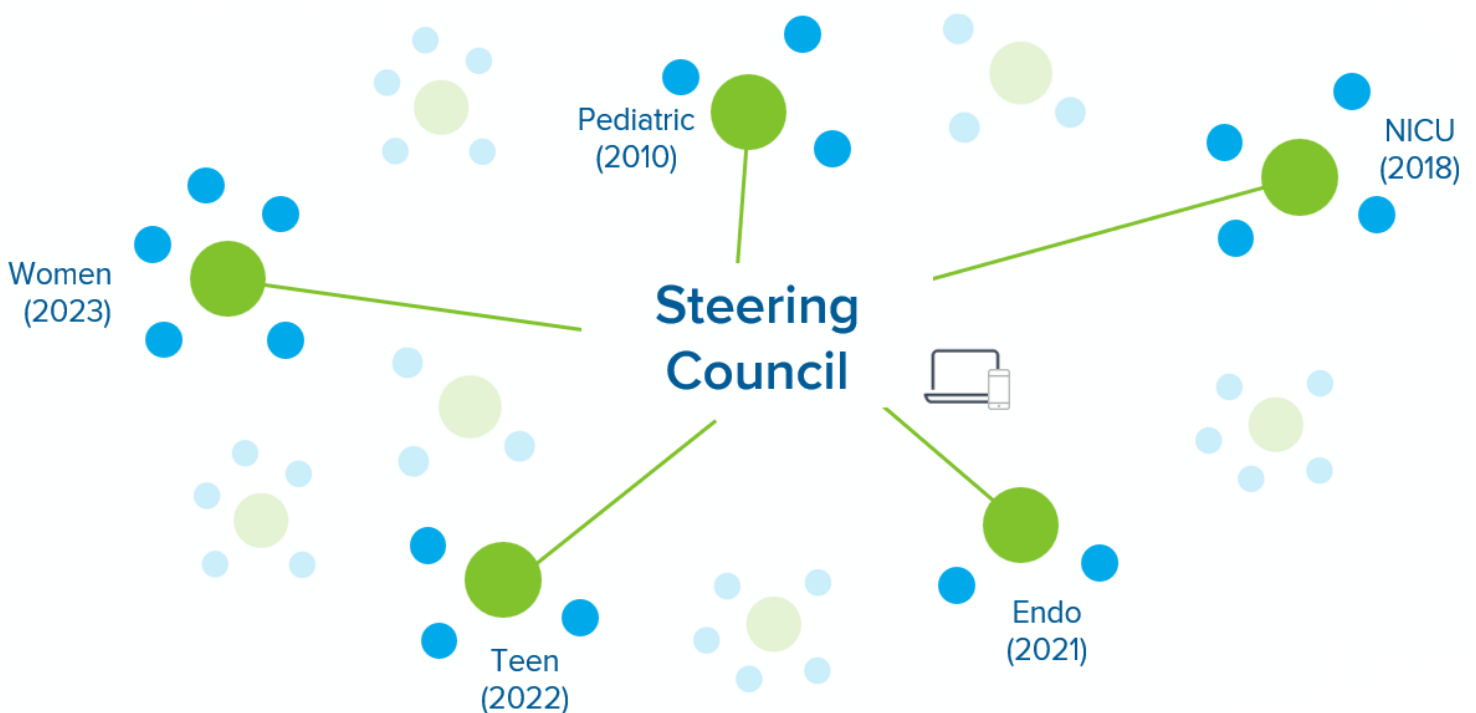
Practicing these principles aligns with the service standards adopted across AdventHealth and are considered as the councils tackle the agenda items discussed at monthly meetings. The PFEP stands behind these standards and the importance of utilizing them with every patient and every time.



*Extending
the healing ministry of
Christ*

Beyond the service standards, the PFEP fully grasps the desire of AdventHealth to provide whole-person care and believes in its faith-based mission to extend the healing ministry of Jesus Christ.

This is what sets AdventHealth apart from other hospitals in Central Florida and across the country. The mission continues to be an important reason why we've chosen to bring ourselves and our families here for care and serve with the hospital to carry on this vital mission.



LIVING OUR MISSION

Longtime goal to launch mentoring program becomes reality

It has been more than a decade in the making, but the PFEP goal of bringing a mentoring program to AdventHealth was finally reached in October. The program is a partnership between Children’s Care Management and the patient experience staff.

The mentoring program is designed to help patients and families cope with their diagnosis. Mentors are trained to share the impact it has on their lives and the tips and tricks they’ve learned to help them cope. Mentoring is not intended to provide or discuss medical information. Those being mentored are urged to talk to their care team to seek answers to those types of questions.

The day-to-day operations will be overseen by Lorena Cabrices-Truong, a licensed clinical social worker, with assistance from Jeff Cousins, the hospital’s family-centered care consultant.

The program will be piloted in the AdventHealth for Children NICU through the end of 2023, with hopes to expand to other pediatric units after that. Several members of the NICU Council are currently being trained. Several parents of babies in the NICU have been identified as ready for mentoring.

The desire to launch a mentoring program goes back to the early days of the council. A major obstacle was finding a children’s hospital with an established program for collaboration. Our new program will be patterned after one at Children’s National Hospital in Washington, D.C. The coordinator, Darlene Jackson, provided legal documents and other information necessary to get started.

“I’m so thankful to Darlene for her help. As a longtime council member, I know how hard we’ve worked for so many years to bring this initiative to AdventHealth for Children. This program is crucial to the whole care we seek to provide to our patients and their families. I can’t wait to see this expand across our hospital,” Cousins said.

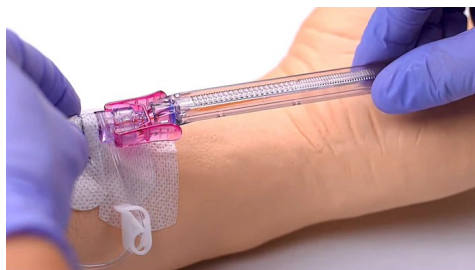
One exciting aspect of the program at Children’s National Hospital is that of peer mentoring. Several members of the AdventHealth for Children Teen Council have said they’re interested in being trained to mentor other patients in the future.



PEDIATRIC COUNCIL

Plan to limit pokes moves forward

The PFEP partnered with the Shared Leadership Quality & Practice Council to seek a trial of a device that would allow children with peripheral IVs to avoid additional pokes for labs.



It began with several requests from staff to bring the PIVO blood collection device to AdventHealth for Children, but the request was initially denied. The council partnered with the PFEP, which decided to write a letter detailing the experiences of parents and patients during a blood draw, as well as the impact it can have on future medical visits.

The letter was signed by members of all the PFEP councils and sent to AdventHealth’s corporate leaders, who then decided to allow the process to move forward.

The hospital is now preparing a presentation for approval to trial the device in the Pediatric Intensive Care Unit. With input from our PFEP, staff and other families, the goal is to get approval for the device in all pediatric areas.

Other accomplishments

- The council participated in an AdventHealth study exploring the value of chaplains in a faith-based health care setting.
- Members of the Pediatric Council organized a well-attended Fourth of July picnic in the Family Resource Center. The menu included hot dogs and cotton candy. Guests could also decorate their own sugar cookie.
- Council members also participated in a survey providing feedback on a Shared Leadership project to expand the products available to provide hair care to all nationalities.



From the chairman

“I appreciate the work of all our council members throughout the year to carefully consider and move forward with so many major projects to truly improve the hospital experience for our patients and their families. This has been a monumental year with the launch of the mentoring program and transitional care task force. I can’t wait to see what’s next.” — **Jenn Sikora, Peds Council Chairman**

MOVING FORWARD

Task force formed to address transitional care

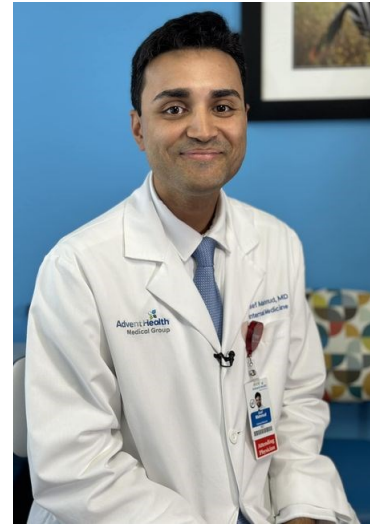
None of us are getting any younger. For most families, the transition from a pediatrician to an adult provider isn't given much thought. But when the patient has a complex history and multiple specialists are involved, moving to a new physician can bring stress and anxiety.

For several years, members of the PFEP have shared frustrations with the process of moving their growing children into the adult hospital. The roadblocks these parents have faced are numerous, including the inability to be accepted by an adult physician, questions about why the patient was admitted to an adult unit, and if so, a lack of availability of needed supplies.

While dealing with these issues, the caregiver must also deal with private insurance and changes to Medicaid and Social Security. It's daunting to say the least.

After several years worth of work, AdventHealth for Children has taken the first step toward building a transitional care program with help from the PFEP. Dr. Asef Mahmud (pictured, right) is a primary care provider for patients who have aged out of the Coordinated Care for Kids (CCK) program. A task force has also been launched with leaders at AdventHealth for Children, AdventHealth Orlando and AdventHealth Medical Group with the goal of bridging the gaps when it comes to inpatient and outpatient services.

The addition of Mahmud has been a welcome first step. He is currently seeing patients at CCK. Future goals of the task force include identifying a location similar to the Pediatric Outpatient Procedure and Sedation (POPS) unit to provide blood draws and infusions and developing a list of adult specialists for transitioning patients.



One exciting sign of AdventHealth's renewed focus on medically complex patients came with the opening of the SMILE with Stella Tremonti Down Syndrome Clinic in October. Mahmud will join Dr. Stacy McConkey to provide a first-of-its-kind Down syndrome program in the Southeast. What sets the program apart is that it will provide care throughout the patient's life.

"Navigating life with a child who has Down syndrome can be overwhelming for parents to do on their own. Individuals with Down syndrome require yearly screenings and testing, bi-annual appointments with cardiologists, orthopedists and other specialists, regular check-ups to monitor hearing and vision, as well as speech, occupational and physical therapies," McConkey said. "To be that central provider holding families' hands along the way and making sure all of the specialists are on the same page, it's incredible to see how our health care professionals come together to make a difference in a child's future."

NICU COUNCIL

Parents offer tips to make rooms feel like home

Creating a warm environment in a patient’s room can help alleviate stress and anxiety, and for some families in the NICU that stay can last weeks or even months.

NICU leaders asked the PFEP to help them avoid uncomfortable situations by creating a brochure to explain how families can decorate their baby’s room while still maintaining a safe environment.

Council members gathered appropriate decorations and also included a checklist of items that can help make the hospital stay more pleasant. They also spent time writing sections of the brochure that were then reviewed by hospital leaders.

A council meeting was held in the NICU over the summer where unit leaders and members decorated a room following safety protocols and took pictures for the publication.

The brochure was completed in November and shared during a morning team huddle. It was warmly received and immediately shared during leader visits to new admissions.



Other accomplishments

- Assisted with creation of flyer on importance of handwashing to prevent CLABSI.
- Provided perspective on best ways to handle code blues when family is away from hospital.
- Shared ideas for room redesign in Grow & Go Nursery.
- Joined hospital group that will participate in statewide effort to improve discharge process.
- Held first Caring by Sharing giveaway to provide gently used clothes, shoes and other supplies to families of babies in the hospital.



From the chairman

“I am so proud of this growing group's accomplishments. Each member fully uses their gifts and talents to improve the council. We have made tremendous progress toward our goals and are looking forward to 2024 with positivity and perseverance. Being part of this council is truly the gift that keeps on giving.” — **Megan Nagle, Chairman**

TEEN COUNCIL

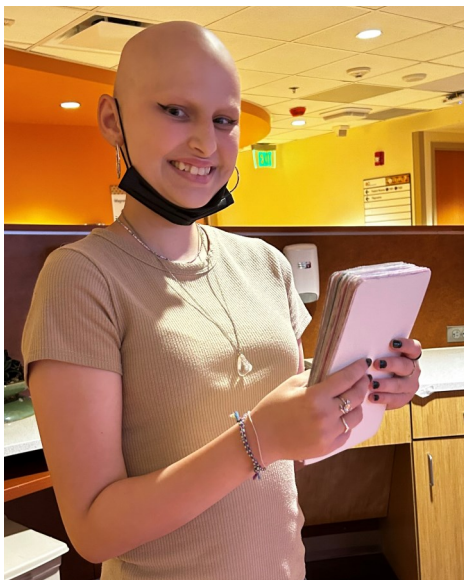
Teens prepare meal for hungry families

Members of the Teen Council visited the Ronald McDonald House in July to prepare a delicious dinner for families of hospitalized children. Spaghetti, garlic bread and salad were on the menu. The group enjoyed the chance to help people in need. Several said they hope to make the project an annual event.



Other accomplishments

- The council embarked on an ambitious project to help clinicians take the time to learn what’s important to their patients when creating care plans. They want to assure their doctor’s goals are in line with their hopes and needs.
- Members created cards for parents of children who have passed away. Hand and footprints can be added to the cards as a memory of the child.
- Members of the council held a Fall Festival for hospitalized kids in October complete with games, food and fun.
- With the hospital’s four new movie channels through Swank Entertainment, the teens have played a role in picking the movies available to patients for each quarter.



From the chairman

“We have accomplished many important goals and continue to set more for the future that will shape and improve the hospital experience for inpatient children and their families. The Teen Council has grown and expanded exponentially, and I’m excited to see where 2024 takes us as we work to further our positive impact and strive to make the hospital a better and more healing place.” — **Julianna Pacheco, Chairman**



ENDOCRINOLOGY COUNCIL

Members assist with transition plans for teens

The Endocrinology Council spent a large part of the year assisting the staff at the clinic with creating plans to assure patients are ready when the time comes to move to adult providers. The council wants to make sure parents are ready, too, when the question is asked of 18-year-olds whether it's OK for the parent to remain in the room during a visit. Plans were reviewed for how to prepare kids each year beginning with their 14th birthday.

Other accomplishments

- Members attended the Touched By Type 1 Diabetes Conference in Orlando in September. Several members of the council who work at the clinic led breakout sessions. The council's Pediatric Diabetes Guide was available at the AdventHealth table, as well as recruitment flyers for the PFEP.
- The council submitted an Action Request Form to Shared Leadership seeking training for inpatient nurses in the use of Continuous Glucose Monitors. The ARF was sent to the hospital's nurse educators and reviewed at a November meeting.
- Staff from AdventHealth Medical Group joined the meeting to seek input on satisfaction with the clinic's telephone system and responsiveness of workers at the clinic. This item is also being worked on by the PFEP at AHMG.



From the chairman

“This was my first full year in the council, and I must say it is truly inspiring. There is such a welcoming aspect of this council that allows you to feel free to share your thoughts and experiences knowing others have had similar ones. I was and still am completely honored that I was nominated as a co-chair and now the chairman. I am thankful for this opportunity to grow as a person and to help build the community.” — **Schneidine Thacker, Chairman**



WOMEN'S COUNCIL

Women's blood drive honoring AFE exceeds goal

A PFEP member's desire to give back led to a hospital-wide effort to collect 100 units of blood during the AdventHealth for Children and AdventHealth for Women town hall meetings in October.

Catherine Garrett was given the blood during a three-week stay to give birth to her daughter. She suffered an amniotic fluid embolism (AFE) during the admission. She is still recovering today.

"While there are many things I'm limited in, one thing that has been really important to me is replenishing the stock I used. I remember when the blood drive coordination team said 100 units would be our goal. I thought they were crazy. I thought we would never raise that. Boy, was I wrong," Garrett said.

The drive collected 109 units, and Garrett is beyond thankful for the support.

"I'm incredibly grateful for the tireless efforts of the AdventHealth staff. From the cafeteria workers to sanitation to the volunteer dog handlers," Garrett said.

To learn more about AFE, visit AFESupport.org.



Other accomplishments

- The October meeting of the Women's Council was devoted to taking the mom-to-be tour of the hospital. Members provided feedback to tour organizers regarding what needs to be included and any questions they still had after taking it.
- The council visited the perinatal high-risk unit to see Jane's Room, a special area for families of patients whose babies didn't survive. They're also working to assure the room is stocked with supplies and educational materials that can help families during traumatic times.
- Council member Crystal Tomlinson and her husband shared their musical talents at the annual remembrance service for families who have experienced a loss.
- The Women's Council will be growing in 2024. With the Florida Perinatal Quality Collaborative's emphasis on social determinants of health, AdventHealth is seeking to include each campus that offers women's services on the council.



From the chairman

"We'll continue our work in key areas that were started in 2023, such as bereavement, mental health and giving back to our healthcare providers. It has been an honor and privilege to come together in our collective efforts to enhance the patient and family experience. We look forward to the continued partnering. Here's to celebrating the great accomplishments over the council's first year." — **Vanessa Mazurek, Chairman**

FAMILY RESOURCE CENTER

FRC operating hours, services expanded

Dozens of guests visit the Family Resource Center every day and operating hours expanded into nights and holidays in 2023.

Interns from the University of Central Florida played a key role in making that happen. On most evenings, the center is open until 8 p.m., with hot coffee, tea, bottled water and snacks available to guests.



Food and beverages are provided by Ronald McDonald House Charities of Central Florida and AdventHealth. Local restaurants also provide lunch to families on Tuesdays.

UCF also worked with AdventHealth for Children’s NICU to begin offering safe sleep workshops monthly beginning late in the year.

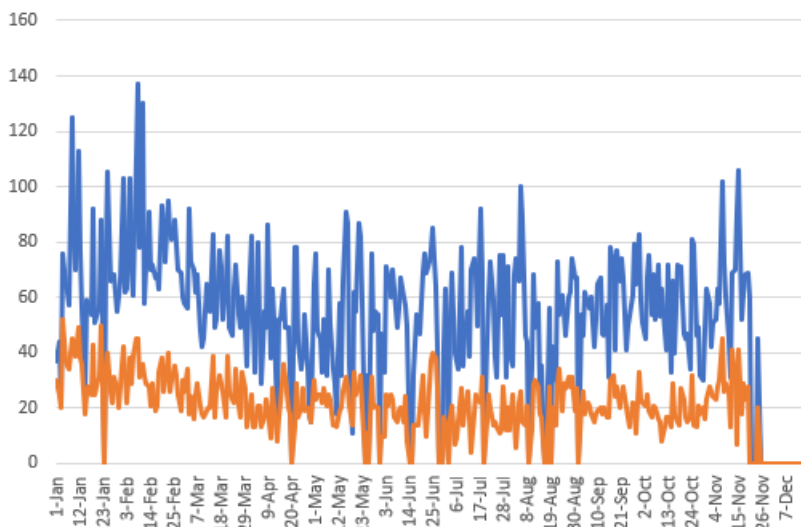
Plans are to also offer CPR education beginning in 2024.

The PFEP and UCF interns provided hospital guests with several special events throughout the year, including a SuperBowl party, Fourth of July picnic, Fall Festival and Christmas party.

For families that couldn’t make it to the Family Resource Center, unit visits began in April with a new hospitality cart from the Ronald McDonald House. The cart typically visits the Children’s Surgery waiting room, Children’s Emergency Center, overflow unit and intensive care units.



Family Resource Center Traffic



Caring in action

My internship at the Family Resource Center was a fantastic experience. The center's primary mission



is to support families during their hospital stays by providing complimentary refreshments and beverages, making these challenging times a bit more comfortable.

From the very first day, I could sense that this would be an empowering and moving experience. Being that helping hand to families in need brings a sense of profound peace and fulfillment. It's incredible to witness the difference a small gesture of kindness can make in someone's day.

One of the most valuable lessons I learned during the internship was the importance of being present for families. We strive to help them with anything they need. Sometimes it's a listening ear, compassion, and support during their hospital stay.

It's not just about providing refreshments; it's about creating an environment where families feel cared for and heard during challenging times.

My experience at the Family Resource Center not only expanded my knowledge of hospital operations but also taught me the significance of empathy and human connection in healthcare. — **Breanna Heatter, Spring '23 Intern**

MEMBERSHIP

Recruitment & selection



Applicants who wish to join the PFEP must complete an application online at AdventHealthForChildren.com or use a QR code (pictured, right). Candidates are interviewed by a staff member and the council chairman before being accepted.

Attributes that are sought in potential members are good listening skills, sharing of thoughts and opinions and the ability to understand differing points of view. The council is committed to ensuring a diverse membership that includes sociodemographic factors including gender, ethnicity, education, employment and income.

Members of the PFEP serve a two-year term and are expected to attend 75 percent of monthly meetings either in person or virtually.

- There are 45 women and six men in the PFEP which includes 40 families and 10 staff members.
- A total of nine new members joined the PFEP in 2023.
- The five councils are overseen by the executive director of family experience and are facilitated by the family-centered care consultant.

	Pediatric Council	NICU Council	Teen Council	Endo Council	Women’s Council
Chairman	Jenn Sikora	Megan Nagle	Julianna Pacheco	Schneidine Thacker	Vanessa Mazurek
Vice-Chairman	Daniel Webb	Maegan Heller	Lazahrya Wright	Kate Perkins	Allison Hurtado
Staff Liaison	Michelle Brandt	Priscila Galeano	Trish Polito	Gilda Gonzalez	Shannon Hughes
	Lorena Cabrices-	Ivy Sterchele	Kelsey Stephany	Nadeen Romain	



LOOKING AHEAD

Councils to focus on patient comfort

The new year is fast approaching, and the chairmen of the PFEP are already making plans to improve the comfort of patients at AdventHealth for Children and AdventHealth for Women. While the hospitals have promoted the use of atraumatic care for many years, members realize this needs to happen with every patient on every encounter.

At November’s meeting of the Steering Council, several members said it’s important that every staff member understands the options available and shares them with families. Members of the Teen Council have been working on individualized poke plans for patients. Finalizing that project could be a key goal in 2024.

The teens have also begun working on education for members of the clinical team to understand the best ways to communicate with them and honor the goals they feel are important on their medical journey.

The journeys for many of our patients are lasting longer— even into adulthood. The PFEP will continue to advocate for a transitional care plan for patients as they reach adulthood. With a task force currently meeting and representatives from AdventHealth Medical Group and AdventHealth Orlando coming to the table, the PFEP is encouraged that there will be considerable progress in the upcoming year.

A decision was also made as 2023 was coming to a close to devote agenda time in all council meetings to educate members on the importance of sharing their stories. This is a powerful way to spread the voice of patients and families in hospital staff meetings. It’s also an initial step for those who choose to join the hospital’s new mentor program.

Members will be encouraged to follow a step-by-step template developed by The Beryl Institute. The plan also helps the storyteller get their thoughts on paper before refining them into a coherent story. They can then be built into short and long versions, as well as be prepared to be delivered in person, via podcast or video.

While the focus of the PFEP in 2024 will be on patient comfort, transitional care and storytelling, each council has ideas on how to continue to give back to our community through our Family Resource Center, staff recognition events and patient mentoring, which is expected to expand from the NICU into the pediatric units over the next several months.

