

# 2024 PATIENT & FAMILY EXPERIENCE PARTNERS ANNUAL REPORT



*Making a*  
**DIFFE**☒**ENCE**



This annual report is dedicated to the memory of:

**Alexis Rose Padgett**

**May 21, 2007 - March 10, 2024**

**Be Creative. Be Kind. Be Determined.**

**#BeAlexisStrong**

#### Cover photo:

Alexis Padgett was a member of the AdventHealth for Children teen council for several years. She died of cancer in March 2024. Council members want to honor and celebrate Alexis' memory and have created friendship bracelets which can be worn and treasured by the group. Each bead of the bracelets symbolizes an aspect of Alexis' life and provides the group with a unique way to express and cope with their grief. In addition to the bracelets, members have written short notes to her family, including everything from funny memories to deeper encouragement.

## ✓ INTRODUCTION

**T**he patient and family voice is making a difference at AdventHealth for Children and AdventHealth for Women through our Patient and Family Experience Partners (PFEP) program.

A sixth council was launched in 2024 that focuses on the SMILE with Stella Tremonti Down Syndrome Clinic. Parents of patients in this lifelong program can now communicate directly with the clinical team to create an incredible experience for this innovative clinic that is welcoming new patients every day.

The pediatric council is now working directly with staff at AdventHealth for Children and AdventHealth Orlando to build on an ongoing initiative devoted to patients in the Coordinated Care for Kids program who are reaching adulthood and could be admitted into the adult hospital.



All the councils joined forces this year to grow our Caring by Sharing giveaway (pictured, below) to patients and families who were hospitalized just before school started at the end of the summer. They were able to find gently used clothes, toys, books and other supplies at no charge.

Our teen council also welcomed patients to a prom at the hospital for those who need a safer environment than can be offered in public. The event was dedicated to a former member who passed away because of cancer.

Our PFEP members closed out 2024 with holiday events for families at the hospital and the staff members who care for them. We invite you to review the many accomplishments of 2024 detailed in the following pages.



## TABLE OF CONTENTS

Introduction: Page 3 Down Syn. Council: Page 10

Philosophy & Vision: Page 4 Women's Council: Page 11

Transitional Care: Page 5 Endo Council: Page 12

Kids TV Launch: Page 6 Family Res. Center: Page 13

Pediatric Council: Page 7 Membership: Page 14

NICU Council: Page 8 Looking Ahead: Page 15

Teen Council: Page 9



## ✓ PHILOSOPHY & VISION

**A**dventHealth for Children is committed to providing the best care possible to our young patients and their families. For the first time, the hospital has been ranked in three pediatric specialties by U.S. News and World Report. While the hospital continues to make strides to be a nationally recognized health destination, the growing number of advisory councils assure the patient and family experience is also unparalleled.

Either as a patient or a parent, our members have seen what makes our system work and where improvements could be made. 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 with care providers.
- Creating a partnership by understanding patients and families are a crucial 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 services standards that guide AdventHealth and are always taken into consideration by councils when discussing matters at monthly meetings. The PFEP also supports the delivery of 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 nation. The mission continues to be an important reason why we've chosen to bring ourselves and our families here for care and serve with AdventHealth to carry on this vital mission.



## ✓ TOP STORY

### Transitional care task force works with adult hospital to improve experience

Thousands of adult patients were seen by pediatric providers at AdventHealth for Children over the past few years.

The pediatric council has a longtime goal to improve the care experience for patients who have aged out of the children's hospital. This initiative gained traction in 2024 when a task force of hospital employees and leaders was established to bridge these gaps in care.

The task force is working with an analytics team to gain more details about hospital stays that involve patients with special needs who were previously treated in pediatric units and later admitted to the adult hospital.

A survey is being developed that will be sent to families of these patients to gauge satisfaction. Caregivers may also be contacted in the months ahead to learn more about their stays.

Meanwhile, the task force is providing education to staff on designated adult units to align with the care received in pediatrics. These units could become the primary locations where these patients could be placed during future admissions. They will also have some of the supplies utilized in the pediatric hospital readily available.

## TASK FORCE ACTION PLAN

- Bridge gaps in care to improve experience of patients and families
- Survey families of prior pediatric patients who have had stays in adult hospital
- Provide education to staff on adult units that could play key role in future plans
- Identify units that could be primary locations where patients with special needs may be admitted



## ✓ CARING BY SHARING

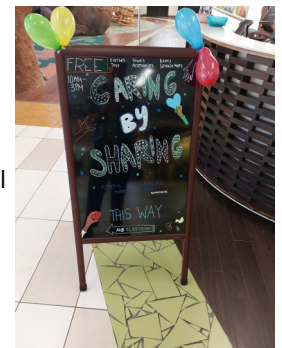
The PFEP at AdventHealth for Children and AdventHealth for Women worked together for the second straight year to hold a Caring by Sharing event just before the start of school. The steering council appointed a task force made up of members from each council to coordinate the event which began as an initiative of the NICU council in 2023.

The task force was able to secure a partnership with Whole Life Church for some of the most needed items, which included clothing and shoes for babies and children, as well as books, toys, games, furniture items and other supplies. Donations were also accepted from staff at the children's and women's hospitals.



The event was held in the Women's Tower classroom and families of patients in the NICU, pediatric and women's units were invited to attend and take anything needed free of charge. Items that were left after the event were donated to the community.

Because of the success of the event, a decision was made to form a year-round task force to work with more local agencies to obtain the items provided at the event and to increase their frequency in the coming year. Some items have already been donated and a storage location has been provided by a council member to hold the donated items.



## ✓ FAMILY-CENTERED CARE

### Kids TV launches at children's hospital

AdventHealth for Children is giving patients the chance to be a star. The hospital launched its Kids TV channel over the summer. The channel is available in all patient rooms and includes entertainment, educational and spiritual programming that is specifically targeted to our young viewers.



During the fall, the channel launched the “Morning Update,” which is produced weekdays and shares important information for patients that includes the child life activity calendar, kid-friendly news, a joke of the day and the weather forecast. Hospital staff members appear often on the program as a way to introduce them to the kids. Following a primetime movie each evening, the channel also airs “Caring for Kids,” a talk show devoted to parents.

AdventHealth for Children would like to thank members of the PFEP for their help with choosing the channel's logo and for their work as a focus group when it comes to developing ideas for programming.

Work is continuing with the teen council to provide members with their own program to connect with patients and aid in recruitment efforts.



#### PROGRAMMING GUIDE

7 a.m.: Friends & Heroes

8 a.m.: CREATION Kids

9 a.m.: Morning Update

10 a.m.: Schoolyard Films

11 a.m.: Music Therapy

12 p.m.: Friends & Heroes

1 p.m.: Be a Mindleader

2 p.m.: Win Win Live!

3 p.m.: Friends & Heroes

4 p.m.: CREATION Kids

5 p.m.: Music Therapy

6 p.m.: Schoolyard Films

7 p.m.: STEM in 30

8 p.m.: Pick the Flick

After Movie: Caring for Kids

## **PEDIATRIC COUNCIL**

### **Focus: Parent meal trays**

A collaborative effort between the pediatric council and hospital leadership resulted in the availability of meal trays for parents of STAR patients. It can be difficult for these parents to leave their child unattended for even a short time. The council is also working closely with nutritional services to revamp the patient menu and enjoyed their role as taste testers for some tasty new kid-friendly entrees.

### **Other accomplishments**

- Pajama Drive:** The council led a drive (pictured, above) that resulted in more than 120 sets of new pajamas for patients and distributed them to rooms during last year's holiday party. The kids were excited to choose their own PJs. The drive is being repeated this year.
- Family Resource Center:** Members played a key role in hosting special events, including movie matinees, a Fourth of July party (pictured, right) and extended hours on some evenings. Family members appreciate having a place to relax and grab coffee or a snack.
- Transitional Care:** An ongoing effort to improve the experience for longtime patients at AdventHealth for Children when they reach adulthood has taken a major step forward with a task force involving leaders from the children's hospital and AdventHealth Orlando. The task force is working to identify specific units that will be specially trained to handle these patients and their unique needs.



“The partnership between parents on our council and our hospital community is refreshing to witness. We truly feel that we are a resource to help improve the experience for patients and families, and appreciate the opportunity to share our input with staff. We are fortunate to have many long-term members and have been energized by the addition of new parents and one of our doctors. We are excited to welcome new members in the coming year that will be moving over from the teen council, to give us the perspective of self advocates.”

— Jenn Sikora, Chairman

## ✓ NICU COUNCIL

### Focus: Homeward Bound

Hospitals across Florida have joined forces to improve the experience of new parents when the time comes to go home from the hospital. The Florida Perinatal Quality Collaborative is leading the effort, and the group wants to make sure the voice of parents is made loud and clear throughout the process. Members of the NICU council are working alongside staff from AdventHealth for Children and participating in virtual meetings with other hospitals. Key components of the improvement plan are being discussed at council meetings. Those discussions have prompted a renewed effort to involve new parents in the care of NICU babies to help these families feel more comfortable when it comes time to take their infant home.

### Other accomplishments

- **NICU Journal:** The council reviewed several options to assist parents with journaling during their baby's NICU stay. Members felt it was important that staff be able to add to their entries.
- **Welcome Video:** A script has been completed for a welcome video that parents will be able to watch when their baby is admitted to the NICU.
- **Mentoring:** A program to allow parents on the unit to partner with a mentor is awaiting launch. Staffing issues have delayed the rollout to the children's hospital, but launch is still expected in 2025.



"I am confident we can grow with more members who are filled with love, insight and stories of hope to share. I look forward to the events we have planned for the Family Resource Center, nurse appreciation, holiday parties, and the mentorship program."

— Megan Nagle, Chairman

## ✓ TEEN COUNCIL

### Focus: Prom

Prom is usually an event that a teenager will remember for the rest of their lives, but some who have medical issues may be unable to attend the event. The teen council provided assistance to the Child Life team to give some patients the chance to experience prom at the hospital – and they created an amazing theme for the night. The council lost a member of their group to cancer this year who had envisioned a theme based on the movie Avatar. There was plenty of food and dancing to give those who attended memories that will last forever.



### Other accomplishments

- **Next Steps:** Some teen council members developed a plan to transition into the pediatric council. They hope to help future patients at the children's hospital, as well as provide input on improving the experience during future admissions of their own in the adult hospital.
- **Art Show:** Patients at the hospital displayed their works of art for all to see, and council members assisted the art therapist with preparations for the event. Some of them even had their artwork shown.
- **Gratitude Cart:** Giving back to the staff is always on the mind of the council members. Many of them have close relationships with the nursing team. They prepared a gratitude cart to visit units of the hospital as a way of showing their thanks to the staff.



“Over the last two years as chairman, I have been blessed to be able to work alongside and collaborate with the other teen council members and child life team. The council has given me an amazing outlet to connect with other individuals going through similar situations and use our struggles to positively impact the stays of future patients.” — Julianna Pacheco, Chairman

## ✓ DOWN SYNDROME COUNCIL

### Focus: Clinical Support

In its inaugural year, the Down syndrome council was excited to support the SMILE with Stella Tremonti Lifespan Down Syndrome Clinic in its first year of practice. The council was made up of eight parents representing pediatric and adult patients. Dr. Stacy McConkey regularly attended each meeting along with the clinic's social worker, a nurse and the clinic's managers. The group was able to share quality information regarding patient and family experiences in receiving medical care in and outside of the AdventHealth system and discussed various support options to improve awareness, build on positive experiences and create resources to increase supportive practices.

### Other accomplishments

- **Ask the Expert:** Creating a list of training topics for the "Ask the Expert" series for the Down Syndrome Association of Central Florida to host.
- **Raise Awareness:** Began a campaign to link the medical community to the national organization, The Down Syndrome Medical Interest Group, to increase practice knowledge for the medical treatment of individuals with Down syndrome.
- **Resource Packets:** Created packets for patients focusing on the Agency for Persons with Disabilities, Social Security and private insurance, as well as others for new babies and general support.
- **Anniversary:** Hosted a one-year celebration at the clinic to show appreciation to staff.



"We look forward to 2025 and the new things the clinic will accomplish. We hope to expand participation, create more tools to support patients to be strong advocates and expand opportunities to increase knowledge of ways to support people with Down syndrome in the medical community." — Soren Richardson, Chairman

## WOMEN'S COUNCIL

### Focus: Bereavement Support

The women's council made tremendous progress in helping families who experience pregnancy or infant loss during their admission. Council members created a care package for patients that can be hand-delivered by their nurse at an appropriate time. The packages serve as a small gesture to provide some comfort items and a note of encouragement during such a difficult time. The group put together 100 packages with the goal of providing support to the units at AdventHealth for Women for one year. The care packages include a heart healing stone, butterfly seed paper, a journal, lip balm, hand lotion and tissues. The first care package was provided to a patient in July. Initial feedback was that the package was unexpected and well-received. The council hopes to sustain the program long-term, leveraging generous fundraising and donations from the community.

### Other accomplishments

- **Discharge Meals:** The council supported the launch of a new program to provide families with a comforting, nutritional meal upon discharge (pictured, below). Intended to help make that first night home a little easier, the first meals were provided in May, and the council had the opportunity to provide input and feedback on the menu items, portioning and package messaging.
- **Patient Education:** Several initiatives were reviewed, and feedback provided, including exploring ways to boost engagement in the Birthly education program before the arrival of the infant and preparing the new family to go home through the Baby Steps to Discharge guide and video-based course.
- **Cookies from the Heart:** The council kicked off their support of the Cookies from the Heart program where council members with a volunteer badge can deliver freshly baked cookies to patients. The council found the cookies provided an avenue for future council recruitment as well to improve the patient experience.



“As we move into 2025, the women’s council is focused on hosting another successful Amniotic Fluid Embolism (AFE) event early in the year to raise awareness, developing a mental health magnet with quick access to key information for women and families post-discharge and furthering bereavement resources available to grieving families, including the expanded use and outfitting of Jane’s Room in the perinatal high-risk unit.” — Vanessa Mazurek, Chairman

## ✓ **ENDOCRINOLOGY COUNCIL**

### **Focus: Diabetes Conference**

Members of the endocrinology council attended the Touched by Type 1 annual conference in September. The council was able to have a table at the event to help with recruitment of new members. The turnout was amazing with some attendees from around the world. One individual was absolutely overwhelmed with her daughter's recent Type 1 diagnosis and was just looking for a listening ear and some support. Everyone at AdventHealth's table welcomed her with open arms, and they provided her with resources for support.



### **Other accomplishments**

- **Insulin Pens:** The council discussed the possibility of using insulin pens for injections at the hospital. The pens use a smaller gauge needle and can be less traumatic for children. Members believe that becoming familiar with the pens would lead to an easier transition to home care. They're working with the hospital's Shared Governance Councils to move the initiative forward.
- **Translational Care Visit:** The council was able to tour AdventHealth's Translational Research Institute and expressed awe with the innovations in health care that are happening there. The group hopes to work together on projects in the future.
- **Resources Area:** The council is working with staff at the outpatient clinic to develop an area there devoted to resources, including those focusing on mental health.



“Joining the council gave my life more purpose. The feeling of giving back, helping others in your same predicament, hearing inspiring stories, thinking back on how things could have been different and working on that change for future families is beyond rewarding. I couldn't be more grateful for this opportunity. I can't wait to see what 2025 brings for our group.” — Schneidine Thacker, Chairman

## ✓ **FAMILY RESOURCE CENTER**

**T**he Family Resource Center is located in the sixth-floor lobby of the Walt Disney Pavilion. The center is open daily and available to family and friends of our neonatal and pediatric patients. The goal of this area is to provide a tangible example of how the children's hospital exemplifies the mission of AdventHealth to extend the healing ministry of Christ and provide family-centered care each day.

The center is managed by the family-centered care consultant along with interns from the University of Central Florida and AdventHealth for Children volunteers. Food and beverages are donated by the Ronald McDonald House Charities of Central Florida and AdventHealth nutritional services. The center offers numerous amenities, including access to computers, printers, charging stations, a shower and a relaxation pod. The center also hosts special events throughout the year.

### **Reflection**

My internship in the Family Resource Center was a bit intimidating at the beginning of the fall semester because I did not know what to expect. I soon realized this area was not just a quick pit stop but rather a place of comfort for families. The center serves as a safe space that allows anxious parents to decompress and ease the pressure of such challenging times.

My focus was to help families feel welcomed and cared for in the Family Resource Center. Just a simple cup of coffee often meant so much more to them. It was an act of care and acknowledgment, so they knew they were not alone. Other ways to offer support could include offering a prayer, listening ear or so much more.

My ability as a Spanish-speaking intern was also an asset: Challenging times can be so much harder when there is a language barrier. I experienced smiles and gratitude when they realized I was able to communicate in their native language. Speaking Spanish was not something that took any extra effort for me, but the simple act of doing so I knew was establishing a connection of support with those individuals.

One of the biggest lessons I learned at AdventHealth is that we never know what someone is going through, so by showing compassion, understanding and kindness, we can make a big difference. I would like to give a thank you to AdventHealth for giving me such an extraordinary opportunity that I know I will carry on during my career in health care. -- Diana Hernandez Fall '24 UCF Intern

"This is the first-choice hospital for my kids. Thank You all!"



## ✓ **HOSPITALITY CARTS**

In addition to sponsoring the Family Resource Center, Ronald McDonald House Charities of Central Florida also provides two hospitality carts for the hospital. The carts are located in the NICU and the pediatric unit on the third floor of the Patient Tower. The cart delivers morning coffee and snacks to newly admitted families and those in our intensive care units each morning. Some of the items available include bottled water, coffee, snack packs and fruit.



"Grateful for all you have been offering myself and my family."



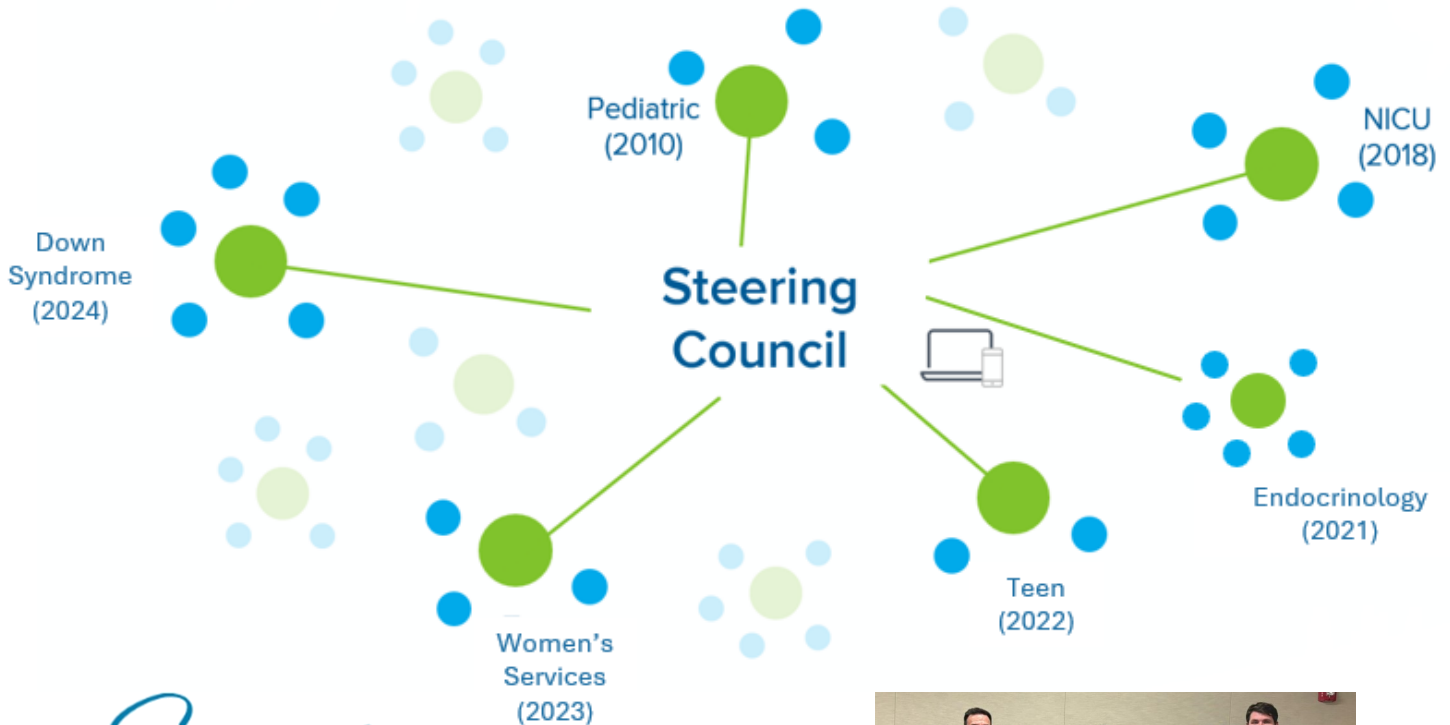
## ✓ **MEMBERSHIP**

**P**atients and parents who wish to join the PFEP must complete an online application that is available on [AdventHealthforChildren.com](https://AdventHealthforChildren.com). Candidates are interviewed by a staff member and the council chairperson before being accepted.

Attributes that are sought in a member include 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 such as gender, ethnicity, education, employment and income.

Members of the PFEP serve a two-year term and are expected to attend nine of the 12 monthly meetings either in person or virtually.

- There are 59 women and 12 men in the PFEP which includes 57 families and 14 staff members.
- A total of 21 new members joined the PFEP in 2024.
- The seven councils are overseen by the executive director of family experience and are facilitated by the family-centered care consultant.



*Extending  
the healing ministry of  
Christ*



## ✓ **LOOKING AHEAD**

**T**he importance of transitional care has been detailed throughout this annual report, but in the past few months the PFEP has realized that it's something we also must tackle internally. The teen council at AdventHealth for Children is growing up and several members worked together on a plan to move to the other councils with primarily occupied by parents.

These dedicated council members are about to enter their 20s and still would like to have a seat at the table because of how much the hospital has meant to them. Through discussions with these members and other council chairpersons, a decision has been made to welcome them to the pediatric council. The group feels this will only enhance the ability of the original council at the hospital to tackle the many agenda items that involve inpatient care, and the perspective of the patient and parent together will be even more fruitful.

As a new year dawns, each council has recognized the importance of developing their stories. It's a vital tool to help members of our clinical teams to understand our patients and families and develop empathy toward them.

With the help of The Beryl Institute's newly published *Stories That Transform: A Guide to Storytelling in Healthcare*, members will continue to write and revise their work with the intention of sharing them in meaningful ways with our staff in hopes of finding common ground and enhancing the experience of patients and families who visit the hospital in the years to come.

As we chart the course for 2025, we must take a moment to recognize the success of our Caring by Sharing giveaway as the beginning of the school year approached. Each of the councils took great pride in gathering and providing the families of our patients with free clothes, shoes, toys, books and other supplies when they needed them the most.

This event will continue – and could happen multiple times throughout the year. A year-round task force is operating and is already forming partnerships to provide items at the next event.

The seven councils of our PFEP program are ready to get to work and continue making a difference at AdventHealth for Children and AdventHealth for Women. Best wishes in the year ahead.

