



# *Sharing* **OUR** **STORIES**

2019 Patient & Family Advisory Councils Annual Report

# Meet Our Family Advisory Council Chairwomen

As the parent of a micro-premature baby, I could have never imagined my child spending his first 115 days of life in a hospital. What was so scary and unsure at the time, I now look back on and remember the comfort and healing provided to my child, myself and my whole family by the nurses, physicians, medical experts and all those involved in caring for us at AdventHealth for Children.

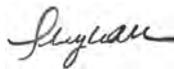
Because of the experiences and interactions we had at the hospital, I had a deep desire to get involved with this hospital. I wanted to give back, get connected with families and children, work alongside leadership and staff; I wanted to be a voice and a part of all the great visions and ambitions this hospital strives to be.

Joining the Family Advisory Council in 2015, I have been overjoyed to be a part of processes that have improved patient care and experiences — not just limited to the hospital but all the networks that are intertwined within AdventHealth.

Our Family Advisory Council makes a difference. We are parents who come together, share our experiences, give feedback to staff and leadership at the hospital, and work together to ensure patients are being put first: Their care is a priority, and they leave knowing that they mattered. Their *whole health* matters.

Throughout this year, the Family Advisory Council accomplished so many of its goals and more. I am so excited to see the impact we will have in 2020.

Sincerely,



SHELBY ALLEN

Shelby Allen joined the Family Advisory Council in April 2015 and is the first chairwoman of the Neonatal Council. She has three children.

If one thing in life is for certain, it's that things always change. Yet are we ever truly prepared when challenges enter our homes and our lives or even families are never the same?

A day such as this knocked at our door and took the hand of health that once was my young, vibrant son. A day that saw us enter into the forever care of physicians and a hospital that promised to stay by our side and heal the whole person every step of the way.

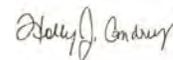
They say it takes a village to raise a child with special medical needs. Never before have I believed this so much as now. It is without question one of the most emotionally and physically tasking roles a child, mother and the entire family finds themselves in.

Now years into the diagnosis and still learning to embrace this new life, I genuinely believe we could not have done so without first, faith in God, and the doctors and staff within AdventHealth who deliver on the mission of compassion-based health care, as well as the support we have found through the advocacy of the Family Advisory Council at AdventHealth for Children.

I am honored and humbled to be a part of this dynamic group of parents as we represent and speak out for many families like mine, and all those past, present and future.

We look ahead to all the new hope that the year 2020 can hold for the Family Advisory Council at AdventHealth for Children. For all things are possible, to those who believe.

Sincerely,



HOLLY CONDREY

Holly Condrey joined the Family Advisory Council in June 2017 and was elected as chairwoman in March 2018. She has two children.

Sharing **OUR** STORIES

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# Year In Review

As 2019 began, so did the official change from Florida Hospital to AdventHealth. Dr. Rajan Wadhawan was also officially appointed the senior executive office of AdventHealth for Children and Dr. Michael Keating was appointed the chief medical officer.



One major accolade the hospital received in 2019 was the recognition of the NICU as best in the state by U.S. News and World Report.

Disney also renewed its commitment to the hospital with the announcement that it would be part of Disney's Team of Heroes, which is designed to reduce anxiety and bring comfort to pediatric patients with an array of experiences, murals and interactive art that will be unveiled throughout the hospital in early 2020.



AdventHealth has invested more than \$80 million in infrastructure and patient-care services on the Orlando campus. This includes the expansion of the emergency department with a three-floor addition, which will make it about 54,000 square feet.



## Our Stories

“The NICU was up and down, one step forward, five steps back. One minute you’re at your breaking point, praying on your knees, then you’re celebrating the smallest milestone that is really quite huge. Through it all, one thing never changed — our hope.”

**Julie Bennett**

**Neonatal Family Advisory Council**



# Accomplishments

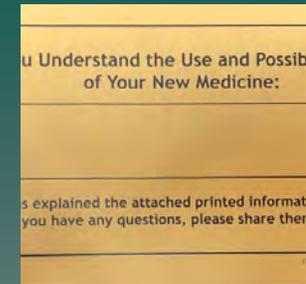
The 2019 Family Advisory Council meetings had packed agendas, allowing the councils to successfully implement many initiatives. The councils tackled some initiatives together and others individually.

## Working Together:

**Golden Ticket:** It is an AdventHealth system initiative, so when it was launched at AdventHealth for Children, the pediatric and neonatal councils played a key role in determining how it could be used to benefit patients and families.

**Patient Portal:** The councils provided members of AdventiHealth system with input on what would help make our patient portal family-friendly. Many members also signed up to participate in an ongoing focus group for digital efforts.

**Environmental Services Feedback:** The councils provided feedback on two occasions. They helped Environmental Services gain a better understanding of the priorities and expectations that families have when they are admitted to the hospital and what they expect to receive from the staff during their stay.



Golden Ticket



Patient Portal



EVS Feedback

# Accomplishments

**Sharing our Stories:** Council members were asked to write a story about a personal experience they had at AdventHealth. These stories have been utilized in this report. Some stories provide insight to the amazing actions of AdventHealth team members, while others focus on the importance of faith. These stories will be used in staff meetings, energizers and other gatherings.

**Water Play the Safer Way:** This packet was created as a summer guide for water safety. It discusses the importance of water safety, the dangers of drowning and what can be done to properly practice water safety. Safety precautions range from enrolling children in swimming lessons to getting certified in CPR.

**Safe Summer Swimming:** The councils helped to create a flyer that discusses primary amoebic meningitis. The handout provided families with the Dos and Don'ts of safe summer swimming to ensure they know the proper precautions to take with children.



Our Stories



Water Play



Safe Swimming

# Accomplishments

## Pediatric Council:

**I-PASS:** This is a process being utilized within family-centered rounds on the pediatric observation and medical-surgical units. It has helped to create more structured communication between patients, families and their care team and helps to ensure that families are actively involved in their care.

**Surgery Cars:** They are being utilized to help alleviate anxiety amongst our youngest patients when they are in the hospital for a procedure. When they are visiting radiology or outpatient surgery, they are able to drive the car to their procedure. The council played a key role in the process for determining which patients would be able to drive the cars and how to explain the initiative to parents.

**GetWellNetwork Revamp:** The pediatric council has assisted in making GetWellNetwork easy for patients and families to utilize for entertainment and education. Members reviewed many of the features of the system and provided feedback on placement.

**Fracture Document:** Members reviewed a document detailing the process for fracture reduction to make it family-friendly and easy to understand.



I-PASS



Surgery Cars



GetWellNetwork

# Accomplishments

**Discharge process:** The council discussed ways to avoid miscommunication during discharge in the pediatric units. They believe miscommunication between providers is a big problem. The council decided on four ways to improve the process:

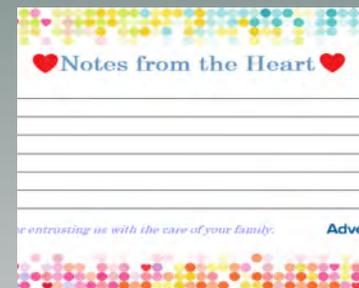
- Caregivers need to be on the same page about the timing of discharge.
- There should be a road map detailing the path to discharge.
- Any opportunity to complete patient discharge forms should be taken before breaks or shift change.
- Confirm patients' equipment and prescription requests are completed the night before or early morning of discharge.

## **Neonatal Council:**

**Notes from the Heart:** These are notes that staff members can write to children and their families. We started a three-month trial in the NICU, and if its effective, the initiative will be launched in the rest of the hospital.



Discharge Process



Notes From Heart

# Accomplishments

**NICU Graduation:** The NICU graduation process was created to celebrate the babies that get to go home with their families. The FAC helped to decide what the cap and gown will look like for the celebration. They also created the ribbon wands that are used during the celebration as the family and baby leaves the unit.

**Milestone Development Packet:** The NICU Developmental Committee created a milestone developmental packet for families. The council was involved by giving input of what was important to families and what the packet should include.

**NICU Walkthrough:** Neonatal council members walked through the 5 East Tower NICU to provide feedback on what was needed within the unit to make parents more comfortable. They found there was a big disparity between this unit and the Women's Tower units. Some recommendations made included painting and renovating the parent lounge.



NICU Graduation



Milestones



NICU

# Accomplishments

**Cookie delivery:** Members delivered cookies to help create connections with families. They were able to receive feedback in regard to family-centered care. When providing cookies, they spoke with families utilizing questions from Child HCAHPS. Many of the parents said they felt an instant connection with council members since they also spent time in the NICU.

**NICU Mobile Application:** The app is being created to help enhance the Whole Care Experience. The goal is to have everything uploaded by the beginning of 2020. This will include a medical dictionary, so parents are able to look up different terms and abbreviations.

**Child HCAHPS Improvement:** The NICU Council was asked what the unit could implement that would help increase their Child HCAHPS scores. One of the answers given was improved communication between staff members. Two other suggestions included a graduation ceremony, which is being implemented, and including parents in milestones for their babies, such as first bath, first bottle or first pacifier.



Gift Basket



Cookie Delivery



NICU Team

# Accomplishments

## Teen Advisory Council

The Teen Advisory Council held several special events for patients and families, including Christmas and winter crafts, prom and a fall festival. The teens have completed numerous projects to assist the hospital's Child Life team.

**Child Life Week:** The teens helped prepare crafts and activities for the month-long Child Life event. Each day had a theme and events were planned around the theme.

**Prom:** This yearly event is held for patients who are not able to attend their high school prom. The event included crafts, food, dancing, photo booth, goodie bags and more. The patients were able to select a dress or tuxedo and have their hair and makeup done by professionals who volunteered their time. The teens helped prepare crafts and decorations before the event and helped during the event at a variety of stations.

**Fall Event:** The teens hosted a fall-themed event for patients during their October meeting with crafts, games and activities.

## Our Stories

“The Teen Advisory Council is an important resource, as our teens are able to provide valuable input to the multidisciplinary team from the perspective of adolescents who have been hospitalized. Our council is also a wonderful opportunity for teenagers to network with other teenagers who have had similar experiences in the hospital and also develop leadership skills. Additionally, the members' contributions to the hospital are a meaningful way for them to give back to AdventHealth for Children and empower them to make a difference in our community.”

Lindsay Smith

Child Life Specialist



# Accomplishments

**Sports Night:** The teens planned and ran a variety of sports-themed activities and crafts during this evening event. Sports included ball toss, basketball hoop, bowling, PS 4 sports games, banner crafts and card games.

**Season's Sweetings:** Coordinated with the Family Advisory Council. The teens had stations set up in the Walt Disney Pavilion lobby where patients and families could make paper ornaments, candy cane reindeers and miniature Christmas tree ornaments to take home or decorate their hospital room.

**Legacy-Making Bracelets:** Braided string bracelets were given to children who have experienced the loss of a family member. These matching bracelets help the children remember and feel a connection with the person who died.

**Partnership with Nutritional Services:** Representatives from Nutritional Services and registered dieticians spoke to the teens about the process of planning and making meals for patients and families. We also took a tour of the kitchen and learned about what goes on behind the scenes.



Teen Advisory Council



Nutritional Services

# Council Overview



Each of the advisory councils allow families to provide their unique perspectives and opinions in regard to decisions that affect patient- and family-centered care. These perspectives often come from members' personal experiences within the hospital. This allows the hospital to partner with families and give them the ability to have a direct impact on the planning, delivery and evaluation of health care. The goal of this partnership is to improve the quality, safety and satisfaction of care provided by AdventHealth.

A mission statement was adopted by the family advisory councils this year. The statement vows to **“Partner with AdventHealth for Children leadership to create a family-centered healing environment and improve the quality of care provided to patients and their families.”**

Each council provides and presents annually on their progress and activities to the leadership team. This annual report will be posted online at [AdventHealthForChildren.com](http://AdventHealthForChildren.com).



## Our Stories

“Dr. Godshall asked, “How are you doing? Did you get any sleep? What can I do to help you?” I was shocked that he asked, that he even cared. The next day I had our son in the room with us when Dr. Godshall came in. Again, he asked, “How are you? Was your night OK?” And then Dr. Godshall sat with my son on the couch, asked him what he was playing on his iPad, and played with him. The compassion I felt in the room was incredible. It was undeniable, Dr. Godshall cared for his patient and her family.”

Faison Weiss

Pediatric Family Advisory Council



# Philosophy & Vision

The overall goal of the family advisory councils at AdventHealth for Children is to promote a positive relationship among the hospital, its families, and the regional community. Therefore, it serves as a vital link between the hospital and its community.



By building and nurturing partnerships across the continuum of care, patients, families and the health care team are able to work better together. The success of this work is based on the principles of patient- and family-centered care:

- ◇ **Dignity and respect:** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
- ◇ **Information sharing:** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and

## Our Stories

“Isabella was in the NICU recovering from surgery during Father’s Day. We all got to visit her. My husband, me, and our 18-month-old son. We had a great time together celebrating in our little room. The nurses were so thoughtful and brought a swing in for Bella so her brother could see her better. It felt like we were home.”

Angela Hanke

Neonatal Family Advisory Council

# Philosophy & Vision

families receive timely, complete and accurate information to participate in care and decision-making.

- ◇ **Participation:** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- ◇ **Collaboration:** Patients, families and the health care team collaborate in policy and program development, implementation and evaluation; in research; in facility design; and in professional education, as well as in the delivery of care.



When it comes to patient experience, the expertise of the council members is fundamental in the promotion of teamwork and effective communication between families and the care team. At the organizational level, members are active partners in safety initiatives, data analysis and care redesign.

## Our Stories

“We did not think he was going to make it. His right lung collapsed. He became very septic, and Dr. Bowen stayed day and night trying to figure out what was wrong. Between a lot of prayer, faith and an enormous team of staff that had a true compassion for children, my son won that battle. Ten years later, we are still fighting, but I thank God for every minute of it.

Mina Robinson

Pediatric Family Advisory Council

# Recruitment

Family Advisory Council members are recruited through communication between AdventHealth for Children staff, patients and families. Applications can be submitted on paper or electronically at [AdventHealthForChildren.com](http://AdventHealthForChildren.com).

Applications are accepted year-round, and candidates are screened and interviewed by hospital staff and council leadership. Once candidates are screened, members are selected based on factors that include listening skills, sharing of thoughts and opinions on health care experiences and the ability to understand different points of view.



## Our Stories

“Environmental Services always made my daughter’s room appear castle-worthy because after all, she was a princess.

The bed would always be clean, pillows fluffed, bathroom spotless, even her personal blankets and stuffed animals would be nice and neat, folded on the foot of the bed. Ms. Rosa made my daughter feel special.”

**Melinda Harris**

**Pediatric Family Advisory Council**



# Member Overview

Members of AdventHealth for Children’s two primary councils, the neonatal and pediatric councils, include parents and grandparents of former patients, as well as hospital staff members. There are 32 women and 5 men, which includes 27 parents and 10 staff members.

The neonatal council has 17 members, and the pediatric council has 20 members. Eight members joined in 2019. Some of the staff members have children who have received treatment at the hospital. The membership is representative of the hospital’s impact across the community and spans across the continuum to include inpatient and outpatient populations.

Members have experiences in pediatric medical/surgical care, hematology and oncology, NICU, PICU, Children’s Emergency Center, bone marrow transplant, and cardiovascular ICU.

The two councils are overseen by the director of family experience, and facilitated by the patient and family experience manager and the family-centered care consultant.

## Our Stories

“The first couple of weeks ran themselves together, learning about ventilators, the medicine, trying to pump, take care of our 9-year old. It was all so overwhelming. But what I do remember is the care, from day one, not just for Nixon, but the whole family. The nurses, the doctors, Child Life, we survived those first couple weeks because of their kindness and compassion.”

Shelby Allen

Neonatal Council Chairwoman



# E-Council

The AdventHealth for Children E-Council was established on Groupsite in 2015 to involve a larger number of families on issues involving patient experience. In April 2018, the E-Council moved to Facebook in order to increase membership and engagement since the social media giant is user-friendly and more popular to use.

Currently, the E-Council has 33 members, which includes many who are also on the Family Advisory Council. The purpose of the E-Council is to keep members informed and to get them involved with different initiatives that are being done at the hospital. It has also created an environment for active discussion regarding important and trending topics in pediatric healthcare.



## Virtual Ideas

The Facebook group has been used to discuss a number of ideas over the past year. Here are some of the popular topics:

- ◆ Adult-sized changing tables in restrooms
- ◆ New products for children with special needs
  - ◆ Dolly Parton's Imagination Library
  - ◆ NICU App
- ◆ Ceremony honors pediatric organ donors and families
- ◆ Teddy bears to hide IV bags
- ◆ Sibling music therapy volunteers

# Council Leadership

The Family Advisory Council has a policy and an election for the nomination and selection of key leadership positions, including chairman and secretary. Positions are solicited through active member nominations and those elected serve a two-year term.

Any active member with strong attendance and a demonstration of a strong commitment to the guiding principles of patient- and family-centered care is eligible. The chairman can serve up to two consecutive terms.

Holly Condrey began her term as chairwoman of the pediatric council in 2018. Shelby Allen began her term in 2019 as first chairwoman of the NICU council. The pediatric council will hold an election for chairperson in 2020.

## Our Stories

“We will never forget the kindness that was bestowed upon us during this challenging time. We are inspired to go above and beyond, and absolutely out of our way to help others now in return. Thank you for those who helped us so much!”

**Ashley Ellis**

**Neonatal Family Advisory Council**



**Advent Health**  
for Children

# Agenda Planning

Meeting agendas are set through a collaborative effort between the patient and family experience manager, family-centered care consultant and the Family Advisory Council chairman. All members of the council are encouraged to bring forward topics of interest, concerns or issues with recent experiences.

Agenda topics also come from various departments at AdventHealth for Children who are seeking input on new initiatives or guidance when it comes to project implementation. In the interest of improvement, each Family Advisory Council meeting allocates time for members to bring up new business and topics for future agendas.

Ideas and recommendations are discussed among council leadership to determine whether they should be placed on the agenda or discussed elsewhere.

Additionally, work is often generated outside of the actual meetings through email, posts to the Family Advisory Council Facebook group or phone calls.

## Our Stories

“Through all this, the NICU nurses were very efficient, however, there was one nurse who came to sit with my daughter as she was there all the time that they allowed daily. She would tell her stories of her younger brother who had Down syndrome. She gave encouragement and a positive view of the future.”

**Pam Taormina**

**Pediatric Family Advisory Council**

# Agenda Planning

Meetings in 2019 were held on:

January 14	February 11	March 11	April 8
May 13	June 10	July 8	August 12
September 9	October 14	November 11	December 9

The November meeting was held in the Woman's Tower classroom and included an evening of food, games and music to thank council members for their contributions throughout the year. The December meeting was used to host the annual Christmas party for the patients and families who were on the units of AdventHealth for Children. Invitations were distributed throughout the units prior to the party.

# 2020 Goals

The Pediatric and NICU councils have several goals for the upcoming year. One of the major goals will be to assist in the creation of a new family advisory council specific to endocrinology.

The pediatric council will hold an election for chairman in 2020. The neonatal council is looking forward to the NICU Reunion event which is scheduled for March 2020. The neonatal council also hopes to address postpartum care for new mothers in the unit.

Both councils are seeking new members and hope to build a diverse membership to ensure that every segment of our population is represented. They would also like to cook dinner for families staying at the Ronald McDonald House.

Another initiative in partnership with the Ronald McDonald House will provide a snack cart for the hospital units beginning in early 2020.

An appreciation event is also being considered for nurses, possibly on Valentine's Day.

Lastly, the neonatal and pediatric councils are hoping to send representatives to the Institute for Patient and Family-Centered Care conference in Nashville in August.

## Our Stories

“We had challenges at home, figured out this new life, and made about four trips back to the hospital for multiple different reasons within the first three months home. But each time, I was always so thankful for the care Nixon received. I just wanted so badly to be a part of this hospital to give back. I always asked the nurses how I could do something — then the FAC was presented to me. Five and a half years later, I'm so thankful for the time I can give back to the hospital and staff who care for my baby boy, me and the whole family.”

Shelby Allen

Neonatal Council Chairwoman



**Advent Health**  
for Children

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