COPING with COVID

Family Advisory Councils
2020 Annual Report

AdventHealth for Children
Meet our Chairmen

Dear Readers,

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. I still reflect on those days and so clearly recall what a rollercoaster ride life was like then. Through the ups and the downs, our time spent in the AdventHealth for Children NICU left an everlasting imprint on my heart. I vividly remember the comfort and healing provided to my child, myself and my whole family by the nurses, physicians, medical experts; all those involved in caring for us at AdventHealth for Children. We still often share our thanks through messages and small gifts, but it doesn’t quite ever seem to be enough to really express our gratitude.

As a result of our experiences and interactions we had with AdventHealth, I had a deep desire to remain connected to the hospital. I was hopeful for the opportunity to be a comfort for other families, a listening ear, a support system to the incredible staff and to 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.

I was so fortunate to join the Family Advisory Council in 2015, just six months after our micro-preemie was discharged from the NICU. 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 mattered.

Every year I am so impressed by all that is accomplished through our council as we continue to get more engaged with hospital procedures and patient care. Our council has strengthened and really connected with the staff and leadership at AdventHealth. Especially this past year, through the unimaginable challenges 2020 presented to our community, nation and world, AdventHealth and our council have pushed forward and never faltered. We have been a support system to each other, to patients and staff (from a distance) and continued to work toward our mission. I have always been deeply grateful for our Family Advisory Council, but now more than ever as we have stuck together through the most challenging times.

I am thankful for the opportunity to serve as the NICU FAC chairperson and look forward to all the great achievements, care and blessings 2021 will provide to our patients and staff at AdventHealth.

Sincerely,

Shelby Allen

Shelby Allen joined the Family Advisory Council in April 2015 and became the first chairman of the NICU Council in 2018. She has three children and works as an elementary school teacher in Orange County.

Coping with COVID 2
Dear Readers,

If there is anything that can be learned from the last few months of uncertainty, it is that while you do your best to plan, you can never be truly ready when crisis strikes.

That moment happened for my family and I back in 2014 when we found out that what we thought was a normal pregnancy with twins wasn’t. It was the news that no parent ever wants to hear: One of your babies has an issue. It was a condition called hydrocephalus. We left the doctor that day with more questions than answers. As the pregnancy progressed, we learned more and more about what to expect when our son was born, and that was that there were no expectations.

When Nicholas was born, he was rushed right to the NICU and our journey with AdventHealth for Children began. I call it a journey because while we have had our ups and downs, the support that we have received from the skilled practitioners and staff is what kept us going. I remember one of his nurse practitioners telling us one day, “You don’t know what Nicholas will accomplish in life yet, because he is still writing those chapters.” That comment stuck out in my brain. That support is what we really needed and what we needed to provide to our son. Nearly six years have passed since he was born, and we have a funny, smart, loving, energetic and strong young man that while he has a shunt in his brain and g-tube in his belly, it doesn’t stop him from working hard while navigating his kindergarten year with his sister and brother in Orange County Public Schools.

It is that experience and the thousands more like it that drives myself and the other members of the Family Advisory Council to serve those families walking the same path we did before them. AdventHealth for Children uses an approach of compassion-based health care with a focus on the whole-person health of not only the child, but also the family.

I am honored to help support the mission of the hospital while also giving those families and patients a voice. We look forward to working toward making all hospital experiences within our facility comfortable, compassionate and collaborative.

Sincerely,

Mike Ollendorff
Pediatric Council

Mike Ollendorff joined the Family Advisory Council in 2016 and was elected as chairman in March 2020. He is married and has three children. He works in communications at Orange County Public Schools.
Coping with COVID

Table of Contents

Year in Review 5
Council Overview 6
2021 Goals 7
PFAC Engagement 8
Accomplishments 9
Philosophy & Vision 12
Recruitment 13
Member Overview 13
Teen Advisory Council 14
E-Council 14
Council Leadership 15
Agenda Planning 15

Staying POSITIVE

“Self-care is incredibly important. Family gets put before everything. There is a lot of peace and joy to be found away from the hustle and bustle.”

— Erin Hinz
Pediatric Family Advisory Council
Member since 2016

After a COVID-19 patient is discharged, the room is deeply cleaned by Environmental Services.
The year began with concern about a virus that was crippling the Chinese city of Wuhan and its population of more than 11 million people. Officials placed the city on lockdown, but it wasn’t enough to stop the novel coronavirus, Covid-19, from spreading. It wasn’t long before news headlines reported outbreaks on cruise ships, then Europe and the United States in a worldwide pandemic.

The agenda for the March meeting of the Family Advisory Council included an update on Covid-19, but few would have believed that just weeks later, AdventHealth would be enacting unprecedented restrictions to visitation, canceling elective medical procedures and redeploying many staff members to assist with temperature checks and screenings for the virus.

The pandemic prompted the cancellation of the April and May meetings of the Family Advisory Council. Updates were provided during that time through email and social media. As the hospital adjusted to the new normal, meetings resumed in June and were held virtually.

The major topic for the year centered around supporting our front-line medical staff, and this report includes details of the numerous efforts by both councils to show the doctors, nurses and other staff how much they’re appreciated.
Council Overview

AdventHealth for Children empowers families and gives them a voice in the decisions that affect patient care and family experiences in several ways.

There are two family advisory councils. One focuses on the pediatric units, and the second is dedicated to the Neonatal Intensive Care Unit.

A teen advisory council also allows the hospital to hear directly from former patients, and an E-council is maintained to garner additional input online.

This partnership allows patients and families to have a direct impact on the planning, delivery and evaluation of health care with the goal of promoting quality, safety and satisfaction.

The councils provide and present annually on their progress and activities to the leadership team. This annual report will also be posted online at AdventHealthforChildren.com.

Each advisory council is guided by the mission, vision, goals and principles which are supported by AdventHealth.

Staying POSITIVE

“The COVID-19 pandemic brought to the forefront the importance of being a responsible citizen and not ignore illness as you can infect many other people and feed the spread.”

— Michael Ollendorff
Pediatric Family Advisory Council Chairman
Member since 2016
2021 Goals

The pandemic provided the advisory councils with an opportunity to explore the growing trend of holding virtual meetings. Previously, there had been several trials using Facebook Live. The trials received positive feedback and there were discussions of allowing members to attend from home. But the inability to hold meetings together at the hospital brought the issue to the forefront.

The idea of providing an option for virtual attendance has several benefits. A potential member’s physical address would no longer be disqualifying, and parents of children with special needs who sometimes are unable to attend because of health issues would be able to participate online.

The work of the councils could also be changed soon:

**New Steering Council:** This council would manage the strategy and goals of all the councils. Meetings would be held in person at hospital monthly, but members could also participate virtually.

**NICU/Pediatric/E-Council:** Meetings become virtual each month to tackle issues and work on projects delegated by the steering council. Recruitment is continuous and members can apply without invitation. Interviews will be conducted before appointment to the council. Membership will mirror the diversity of patients served at the hospital. Breakout rooms would be utilized for topics specific to NICU and pediatric groups.

**Teen Advisory Council:** There is a possibility of meeting virtually, as well. This council would also work closely with the steering council and have representation there.

**Spanish Advisory Council:** A new council would be made up of parents in the Hispanic community. Some bilingual members would also be included in the steering council.
PFAC Engagement

The desire to increase the number of members and make it easy for them to attend council meetings is just the beginning of an overall effort to build on the culture of family-centered care at AdventHealth for Children. Recognizing the unique strengths of each member and learn more about their interactions with the hospital will allow greater engagement based on their availability and desires.

Educating all our advisory council members is also paramount to building a more effective advisory council for the hospital. Future agendas would follow a standard meeting structure to review goals, discuss challenges and share successes. Meetings would also include:

**Education:** Provide members with a greater understanding of the issues faced in the hospital, including CLABSI, diversity, education, health policy, Magnet process, marketing, performance improvement, pharmacy and volunteer services.

**Leadership Training:** Build effectiveness in members with topics on confidentiality, parent perspectives, how to share the floor, authority of FAC, gaps in care, family-centered care, what to know when child is hospitalized and boundaries.

**Meet and Greets:** Invite unit and hospital leaders to meet members of the council.

**Quarterly Summits:** Provide a panel of parents to the hospital for feedback on important issues such as hand hygiene, digital health, equity, skin injuries, nutritional services.

Debrief sessions following each meeting will also allow members to ask additional questions about what they’ve heard and learned at meetings, as well as gauge interest in future agenda topics.
Accomplishments

Agendas were greatly impacted by the Covid-19 pandemic. The family advisory councils shifted gears when meetings resumed virtually in June. A decision was made to do everything possible to support the front-line staff on the units of AdventHealth for Children, as well as some staff at AdventHealth Orlando.

**Nurse Appreciation:** Care packages containing sweet treats and words of encouragement were provided by both councils to nurses in the NICU, pediatric units and other staff members. Members collected the treats and staff members on the councils went unit by unit to distribute them.

**Meal Delivery:** At the height of the pandemic, several council members took it upon themselves to collect money and coordinate a food delivery to AdventHealth Orlando for those workers who were working with adult patients in the Covid-19 units.

---

**Staying POSITIVE**

“Being 'forced' to stay home helped us realize how lucky we were to be able to be home with our children, spending more quality time together.”

— Shelby Allen

NICU Family Advisory Council Chairman

Member since 2015
Accomplishments

**Staff T-Shirts:** A pediatric council member worked to have T-shirts created to remind AdventHealth for Children’s nurses that they’re true superheroes. Several deliveries were made, and the shirts brought smiles to many faces.

**Personal Hygiene Kits:** With many parents facing long stays in patient rooms with their children, a NICU council member put together 50 personal hygiene kits to be distributed to those in need. They contained travel-sized items, toothpaste and toothbrushes.

The advisory councils were also involved in three action request forms in conjunction with the Shared Leadership Council.

- **Caring Bridge:** A staff member filed an ARF regarding the possibility of using an online platform to provide parents with an easy way to update multiple people on the condition of their child. The council provided feedback.

- **Quiet Time:** A unit practice council was interested in incorporating a two-hour quiet time during the afternoon. Members shared that they agreed with the idea.

- **Discharge Medications:** The Family Advisory Council submitted an ARF regarding confusion with liquid medication dosages and asked that prescriptions and discharge paperwork include the dosage in both milligrams and milliliters.

Work also continued on several other projects unrelated to the pandemic.

- **Hospitality Cart:** The Ronald McDonald House Hospitality a la Carte began visiting inpatient units in July. The cart supplies drinks, snacks and other items to parents of patients. The council has worked with volunteer services...
Accomplishments

to staff the cart.

**Transitional Care:** A longtime concern of members has been what happens to children with special needs when they become adults. It’s a national issue, and hospital leadership has now moved forward with a committee to develop a plan. This project will continue in 2021.

**IV Infiltrates Document:** A HAC workgroup wants to involve parents at bedside with helping to protect patients from infiltrated IVs. They shared a proposed document that shows what to watch for. Feedback from the council will be used to finalize the paper.

**Family-Centered Care Assessment:** All units at the hospital completed an evaluation on family-centered care. Numerous members of both councils also provided feedback for the evaluation. The assessment will be used to develop plans for individual units in the months ahead.

Additionally, an initiative by the NICU council to create a graduation process for infants at discharge was included in the hospital’s application for Magnet recertification.

The councils also moved away from member binders and launched a new website that includes agendas and minutes.

**Staying POSITIVE**

“I think the world is becoming more mindful of germs as a whole, and that’s very helpful for us as medically complex parents.”

— Grace Smokay Larson
Pediatric Family Advisory Council
Member since 2019
Philosophy & Vision

The Family Advisory Council’s goal is to promote a positive relationship among AdventHealth for Children, its families, and the regional community, and thereby serve as a vital link between the hospital and its community.

By creating partnerships across the continuum of care, patients, families and the health care team work together. The success of this work is based on 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 families receive timely, complete and accurate information to effectively 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, health care practitioners, and health care leaders 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.

On the experience level, the expertise of council members is fundamental in promoting teamwork and effective communication. At the organizational level, members are active partners in safety initiatives, data analysis and care redesign.
Membership Overview

Recruitment & Selection
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. They are accepted year-round, and candidates are screened and interviewed by hospital staff and PFAC 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.

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 29 women and five men, which includes 24 parents and 10 staff members.

The neonatal council has 14 members, and the pediatric council has 20 members. There were three new members in 2020. Some of the staff members have children who have received treatment at the hospital. The membership is reflective 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, 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.
Other Councils

Teen Advisory Council Overview

E-Council Overview
The AdventHealth for Children E-Council was established in 2015 to provide a larger number of families from which to draw input on matters being addressed by the Family Advisory Council. Comments from the E-Council are frequently mentioned during Family Advisory Council meetings.

The E-Council has been most successful when issues arise between monthly meetings of the Family Advisory Council, particularly with questions that require a simple yes-or-no answer or those of which a choice needs to be made between a limited number of possibilities. Questions that require more thought have garnered few responses, and membership on the E-Council currently consists mostly of Family Advisory Council members.

Staying POSITIVE

“I’m thankful for my health, my son, friends and being able to be back volunteering at AdventHealth for Children. Every day is a blessing.”

— Dona Horn
Pediatric Family Advisory Council
Member since 2012
Leadership & Planning

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

Shelby Allen is currently serving as chairwoman of the NICU council, and Mike Ollendorff was elected as chairman of the pediatric council in March.

Agenda Planning
Meeting agendas are set in a collaborative manner by the Patient and Family Experience Manager, Family-Centered Care Consultant and the Family Advisory Council Chairpersons. Members are encouraged to bring forward topics of interest, concerns or issues with recent experiences. Agenda topics also come from various departments at Florida Hospital for Children who are seeking input on new initiatives or guidance in project implementation. In the interest of improvement, each Family Advisory Council meeting provides time for members to bring up new business and items for future agendas.
Conclusion

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

Work is often generated outside of the actual meeting through email, posts to the Family Advisory Council Facebook group or during phone calls.

Meetings in 2020 were held on the following dates:

<table>
<thead>
<tr>
<th>Jan. 13</th>
<th>Feb. 10</th>
<th>March 9</th>
<th>April 13*</th>
</tr>
</thead>
<tbody>
<tr>
<td>May 11*</td>
<td>June 8</td>
<td>July 13</td>
<td>Aug. 10</td>
</tr>
<tr>
<td>Sept. 14</td>
<td>Oct. 12</td>
<td>Nov. 9</td>
<td>Dec. 14*</td>
</tr>
</tbody>
</table>

* Canceled because of Covid-19 pandemic

The November meeting was heavily devoted to a holiday party for members. The December meeting date is usually used to host a Christmas party for patients and families, but that did not happen because of Covid-19.