



Johns Hopkins Children's Center Patient- and
Family-Centered Care
Annual Report 2013

An Overview of Major Achievements



JOHNS HOPKINS
CHILDREN'S CENTER

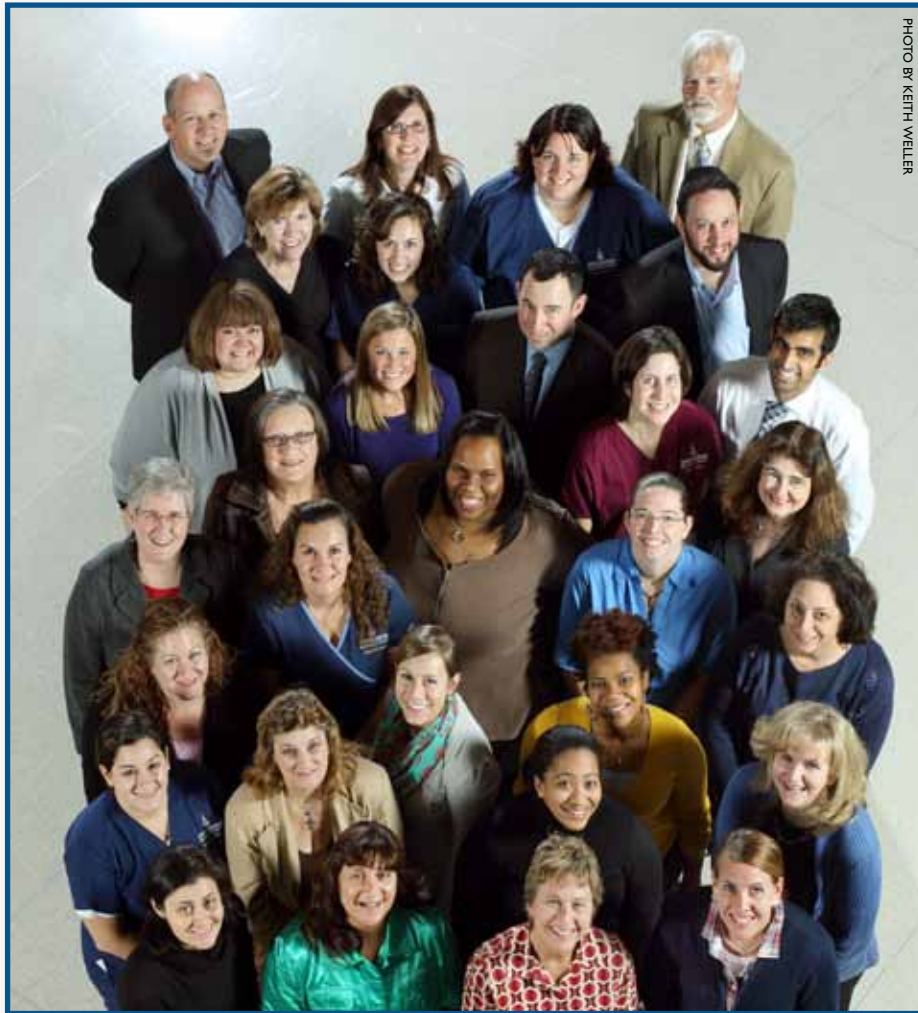


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Pediatric Family Advisory Council 2013-14



When parents and medical staff work together as a
TEAM, they are unstoppable.

Ali Lazorchak, Family Advisor



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“Happy Birthday” Pediatric Family Advisory Council

by George Dover, M.D.

It’s hard to believe our renewed patient- and family-centered care initiative took off with just a handful of staff and parents in a small conference room in our old hospital seven years ago. And with all of its institution-wide activities since then, one could equate the energy of the group with that of a relentless 7-year old. But at the same time these family-focused pioneers took a patient and thoughtful strategic approach to make sure that the programs they developed would advance the principles of patient- and family-centered care in tangible ways. Their aim was to not only effect change here but regionally and nationally, too, as a model program. Have they succeeded—and if so, how?

First off they built a philosophy of what patient- and family-centered care should be at a children’s hospital. They did their research, consulted the experts, and visited children’s hospitals with strong family-centered care programs nationwide. They came home and established their own foundational pillars like collaboration, dignity and respect, and participation—hallmarks that would deliberately permeate each future activity they pursued. Next they created an organizational structure, called the Pediatric Family Advisory Council, that would engage Children’s Center staff and transform their thinking into substantive change.

Among those changes you’ll read about in this annual report was the establishment of family-centered rounds to give parents more of a voice and to formally invite them to be members of the health care team, and the creation of a new full-time Parent Advisor position to give our parents a representative seat at the table in operations committees and at the highest levels across the Children’s Center. Now Pediatric Family Advisory Council members are developing new initiatives like its spin-off Youth Advisory Committee, a virtual e-Advisor proposal and a “Family as Faculty” program, in which parent advisors offer the “parents perspective” on a wide range of issues at new employee orientations and nurses and residents’ conferences, among other settings. And that handful of pioneers has evolved into a FAC with over 50 members—more than half of whom are parents.

Indeed, we’ve experienced a cultural shift. Family-centered care is now at the forefront of an unbelievable number of conversations each day here at the Children’s Center, and more and more we’re putting ourselves in the shoes of parents before making decisions, which is changing our culture. That, perhaps, is the most substantive change.

I commend our Pediatric Family Advisory Council leadership and members—and wish them a “Happy Birthday.” We all expect they’ll be just as active over the next seven years.



Our Core Values

In the early days of developing an innovative new patient- and family-centered care initiative, we determined that its foundation needed core values or pillars from which we could build and grow activities and programs. In each new initiative, we try to incorporate these values, which include:

Dignity and Respect: We believe that an essential component of patient- and family-centered care is listening to and honoring patients and families' perspectives and choices. We constantly strive to incorporate patient and family knowledge, values, beliefs and cultural background into the planning and delivery of care.

Information Sharing: Only through an authentic and transparent dialogue can patients and families effectively participate in care and decision-making. We believe health care practitioners should communicate and share complete and unbiased information with patients and families in affirming and useful ways.

Participation: We encourage patients and families to participate in care and decision-making at the level they choose.

Collaboration: We invite patients, families, health care practitioners and hospital leaders to collaborate in the development, implementation and evaluation of programs ranging from health care facility design to professional education, as well the delivery of care.



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Our Mission & Vision

The mission of the Johns Hopkins Children's Center is to provide patient- and family-centered care in a diverse and inclusive environment, to be a leader in innovative research that leads to prevention and effective treatment of childhood diseases, and to train the next generation of leaders in pediatric medicine.

By promoting a culture of patient- and family-centered care at the Children's Center, and by providing resources and guidance to strengthen collaboration, communication and mutual respect between the health care team, patients and their families, the members of the Pediatric Family Advisory Council believe the highest quality outcomes possible can be achieved.

How We Work

What's our *modus operandi*—our method of operation? How do we function? In setting our goals and initiating actions to achieve them, we rely on input from the full rank and file of the Pediatric Family Advisory Council, as well as our executive committee and subcommittees designated to focus on certain areas, like family activities, membership and peer mentoring. We meet monthly and invite leaders across the Children's Center to inform us and receive our feedback. For example, a member of Infection Control may give us a presentation on how the team operates and solicit our feedback on how parents can best be involved. Or a neonatology researcher may talk about an initiative to improve fathers' involvement with high-risk infants in the NICU and ask for our thoughts. Other topics include a comfort plan for procedures and pokes, the hospital's "Language of Caring" program, and an early discharge planning initiative.

Our members sit on various hospital operations committees to offer the parents' perspective on policies. We also conduct workshops on topics like storytelling, a hallmark activity of the Pediatric Family Advisory Council. At each monthly meeting one or two staff or parent advisors will tell their story to help us all have a better understanding of the experience a seriously ill or injured child brings to the family and the health-care team. Our annual retreat in September allows us to reflect on activities and achievements over the past year and to prioritize and plan new ones for the next.

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FAMILY MEMBERS ARE HERE TO PARTNER WITH STAFF, and review and craft policies. They draw from their health care experiences and make recommendations on how to improve aspects of care from the family's perspective. *Pamela Griffin, Parent Advisor*

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2013 Initiatives

- Family-Centered Rounds
- Family as Faculty
- Improving Discharge
- Making the Most of MOLST
- Pediatric Residency Milestones
- Reducing Bloodstream Infections
- Celebrating a Special Week for Families
- Promoting Pastoral Care
- Using Our Voices
- Telling Our Story





“ We see a burgeoning area of research examining family-centered rounds, but MOST OF THIS RESEARCH HAS CONCENTRATED ON FAMILIES’ PERCEPTIONS. No studies have looked at the family centered care experience from a 360 degree view. *Megan Tschudy, M.D., pediatrician* ”

Family-Centered Rounds

Since 2008, families have been invited to participate in traditional medical rounds designed for residents and medical students at Johns Hopkins Children’s Center. Staff tell us that the new Family-Centered Rounds have helped participating families become more proactive and confident—and less anxious—about their children’s care. Others have noted improved quality of care because residents and other members of the health care team are receiving more information about each child.

The rounds continue but with the added focus of determining how they can work better for families and clinicians. In 2013, for example, pediatrician and FAC member Megan Tschudy led an unprecedented research project utilizing focus groups of case managers, Child Life specialists, medical students, nurses, parents, pharmacists and residents for an in-depth, multiple-perspectives look at Family-Centered Rounds. Through collaborative discussions the focus groups identified

barriers to effective patient- and family-centered care at Johns Hopkins, and explored ways to improve family and medical team communications, partnerships and teamwork.

Family as Faculty

In 2013 the Pediatric Family Advisory Council continued to develop its “Family as Faculty” program in which parent advisors share their personal experiences with staff in various settings, including new staff orientations and nurses and residents’ conferences. Pediatric Residency Program Director Janet Serwint noted that members oriented new interns to the roles of members of the Pediatric Family Advisory Council and its resources and opportunities. Also, parents shared their perspectives on their child’s hospitalization to help new trainees better understand what hospitalization is like for families. Parent advisors also shared helpful feedback regarding what parents appreciate and value from the medical teams.

Improving Discharge

Pediatric Family Advisory Council participation in the Johns Hopkins Children's Center's latest discharge improvement project, noted research associate in the Division of Quality & Safety Nichole Persing, was critical to its success. Families' input, particularly their adamant belief that parents begin thinking of discharge the moment they arrive, helped put more focus on the patient and family's experience in leaving the hospital, she said. The result? A redesign of workflows to achieve safer and more timely discharges.

In a related initiative engaging the Pediatric Family Advisory Council in March 2013, a collaborative effort began between multidisciplinary members of the Johns Hopkins Children's Center inpatient care team and the Arcade Pharmacy leadership to improve the discharge prescription process. In June 2013, this partnership expanded to help improve the experience of patients and families in the inpatient environment. Participation in monthly multidisciplinary meetings led to new ways to improve all areas of care for patients and families from hospital admission to discharge.



Parents saw MOLST as an important component of family-centered care that would EMPOWER THEM TO FEEL CENTRAL TO THEIR CHILD'S CARE.

Pam Donohue, neonatology researcher



Making the Most of MOLST

When Maryland state officials announced earlier this year that the state would be the first to mandate Medical Orders for Life Sustaining Treatment, or MOLST, for hospitalized children, Pediatric Family Advisory Council members put their investigator hats on to help guide the development of new regulations. To better understand existing practices of pediatric advance care planning and how MOLST would impact health professionals and parents' expectations, a study was conducted by Children's Center faculty and parent advisors. Pediatricians and nurse practitioners were also recruited for the clinician perspective.



In this discharge improvement initiative the voice of the customer was key to a successful outcome... Having the opportunity to partner with our parent advisors and the Pediatric Family Advisory Council helped us better understand that voice.

pediatric hospitalist Susan McFarland, M.D.



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The INVOLVEMENT OF THE PEDIATRIC FAMILY ADVISORY COUNCIL HAS BEEN INCREDIBLY VALUABLE to our residency training program and I continue to seek their wisdom and input.

Janet Serwint, M.D.

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Reducing Bloodstream Infections

Efforts to prevent and reduce central line associated bloodstream infections (CLABSI), which are associated with bad outcomes, continued in 2013 with participation by the Pediatric Family Advisory Council and parent advisor Stefanie Fay. “We loved having her as a family advisor at the table,” said pediatric intensive care nurse Judy Ascenzi, a member of the hospital’s CLABSI committee. “The commitment from her and us shows that we want to have a partnership with our families. We also think her presence helps us tackle issues that are more patient centered, such as continuity of care across units.”

Achieving Pediatric Residency Milestones

When Pediatric Residency Training Program Director Janet Serwint faced a new requirement by the Residency Review Committee that pediatric residents be evaluated in 21 domains of “Pediatric Milestones” competencies—including such components as medical knowledge, transition of care, effective communication and interacting with patients in a compassionate and humanistic manner—she sought input from the Pediatric Family Advisory Council. She was not disappointed: “The involvement of the Pediatric Family Advisory Council has been incredibly valuable to our residency training program and I continue to seek their wisdom and input.”





Promoting Pastoral Care

Johns Hopkins pastoral care program has evolved from a single chaplain to a staff of five fulltime chaplains and a robust Clinical Pastoral Education training program. This past year, with funding to hire a chaplain dedicated to pediatric patients and families, members of the Pediatric Family Advisory Council provided input to ensure the pastoral care program reflects the core concepts of patient- and family-centered care. In that regard, they and an interdisciplinary multi-faith group developed a survey for families and staff to determine what spiritual support services are needed and how best to provide them. The findings, noted Matt Norvell, newly named pediatric chaplain for the Johns Hopkins Children's Center, will lead to pastoral care tailored for patients and families.

Celebrating a Special Week for Families

In March 2013, members of the Pediatric Family Advisory Council hosted the Children's Center's annual "Patient- and Family-Centered Care Week," featuring activities emphasizing the hospital's family-centered approach to care. Among the highlights, Grand Rounds keynote speaker Tiffany Christensen, a nationally known patient advocate. Born with cystic fibrosis, Christensen has spent a lifetime developing strategies for coping with chronic illness and navigating the health care maze. Other activities during the week included coffee hours for parents, arts and crafts sessions, and special play activities for patients and siblings.



This project breaks new ground in our institution by INCLUDING FAMILY MEMBERS AS PARTNERS WITH AN INTERDISCIPLINARY TEAM to investigate the best programs for providing spiritual support to patients and their families. *Children's Center Chaplain Matt Norvell*





The words of advice have been a learning experience not only for parents but for our hospital staff, too, in BETTER UNDERSTANDING THE PATIENT EXPERIENCE and the family perspective.

*Beth Bounds,
chair of the Pediatric
Family Advisory Council's
Peer Mentoring Group*



Using Our Voices: “We’ve Been There, Too”

At several monthly meetings of the Pediatric Family Advisory Council, members have expressed the deep desire to help other parents and families cope with the diagnosis and hospitalization of their children and their post-discharge care. Their personal experiences have value, parent advisors concluded, but what’s the best way to share them to help other parents? That question led to the conception and months-long development of “We’ve Been There, Too,” now an accessible audio page in the Children’s Center’s website in which parent advisors share—in their own voices—brief but insightful recorded reflections of their children’s hospital experience that likely will hold value for other parents. Among the topics—adjusting to a chronic medical condition, coping with long-term hospitalization, and chronicling your child’s care.

“Your Voice Matters”

Parent advisors know that the hospital can be a scary and confusing place for children and even parents. So, to help both patients and their families adapt to a hospital stay, a group of parent advisors, led by Pediatric Family Advisory Council member Sue Mead, created a parents journal to help them gain control over an often unpredictable experience in their life. Information in the journal ranges from definitions of medical professionals and where to find parking coupons to meaningful quotes and helpful hints from other parents of a hospitalized child.



Telling Our Story

With a member of the Johns Hopkins Children's Center Public Affairs staff serving as a standing member of the Pediatric Family Advisory Council, we've proactively promoted a number of our activities over the past year, including—

- Coverage of monthly Pediatric Family Advisory Council meetings and “Patient- and Family-Centered Care Week” in internal e-letter *NewsLink*, *Hopkins Children's Magazine*, the Children's Center website, and *The Dome*.
- Development and publication of a standing “Family Matters” column by Parent Advisor Pamela Griffin in *Hopkins Children's Magazine*
- Development of the “We've Been There, Too” web page featuring FAC parent advisors' audio vignettes designed to connect with parents of a seriously ill or injured child.



“Sharing our common experiences, we've learned, can make all the difference in the world for a parent with a child in the hospital.”



Pamela Griffin, Parent Advisor on Staff at Hopkins Children's Center, can be reached at HopkinsChildrenEAC@jhmi.edu

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 In developing this journal for parents,
 we asked ourselves, ‘WHAT WOULD
 HAVE HELPED US WHEN WE STOOD
 IN YOUR SHOES?’
 Sue Mead, parent advisor



Electronic news editor Elizabeth Treary, center, uses a parent's vignette designed to support other parents with a seriously ill or injured child. Looking on is FAC member Beth Bonds, at right, who is leading the “We've Been There, Too” initiative.



The Charlotte R. Bloomberg Children's Center



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