



# PATIENT AND FAMILY ADVISOR PARTNERSHIP PROGRAM

PROGRESS REPORT 2016



**U**W Health is proud to have one of the most robust and active Patient and Family Advisor Partnership Programs in the nation. Nearly 200 Patient and Family Advisors (PFAs) serve on 12 Patient and Family Advisory Councils (PFACs), as well as dozens of work groups, councils and committees throughout our organization – all in an effort to help us continually improve the quality, safety and experience of our care.

This progress report is a mere snapshot of the many improvement efforts underway and the far-reaching impact of PFAs' insights and contributions. Thanks to all of our PFAs and to our leaders and staff who are working alongside them to strengthen our culture of patient- and family-centered care.

---

## REFLECTIONS

By Sandy Salvo, Program Manager, Patient and Family-Centered Care



At the time of my retirement in January 2017, I will have served in this role for almost four years. I have been honored to have had the opportunity to lead the growth of the PFA Partnership Program from the strong base established in earlier years, and to watch the impact of our PFA voices resonate across UW Health.

I wish to thank each of our past and present PFAs who have inspired me over the years by volunteering their passionate and inspiring perspectives to help us transform the way we deliver care. Each of you came with your own story and set of experiences. I have been honored to hear them and share in your journey.

In one of my earlier career transitions a wise friend shared this quote with me and I have kept it in clear sight at work and at home ever since: “Keep what is worth keeping, and with a breath of kindness, blow the rest away.” Be assured, my friends, that your stories will be coming along with me as I transition into a new chapter.

With deep gratitude,  
Sandy

# IMPACT

## Improving the Preoperative Patient Experience

By Kristen Cassarini, PFA

I really enjoyed being part of the Orthopedic Clinic's improvement project at The American Center. The clinic leaders established that they wanted to address pre- and post-surgical education for surgical hand patients, but left how that looked up to the group.

As a recent surgical hand patient, I was excited to work alongside various staff and providers on the project. We really took apart the process, going step by step from the decision to have surgery to the day of procedure and did it from both the patient/caregiver and staff perspectives. By doing this, we were able to pinpoint key issues that would repeatedly come up and then collaborate to create change.

We refined the after-visit-summary dot phrase (electronic medical record shortcut), created a handout that lays out the pre-surgical process for the patient/caregiver and systematically applied both of them throughout the clinic. The group was very receptive to hearing the PFA perspective and took it a step further by surveying other patients on their day of surgery to gather more information.

I'm really excited, not only about our results, but that the Orthopedic Clinic continues to keep the patients and their caregivers at the forefront. Our changes have been implemented throughout the Hand Surgery Clinic at The American Center and are now being used to collaborate with other clinics to share what we learned. It has truly been one of the most interesting and rewarding PFA projects I've worked on.



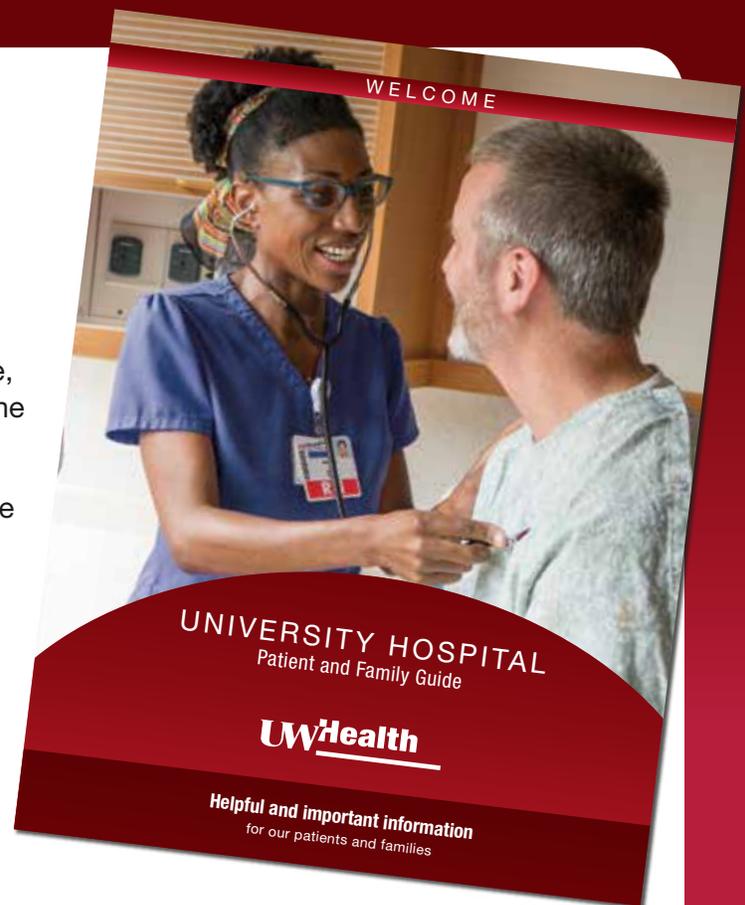
*"Kristen was instrumental in our project. She's had surgeries at The American Center and was able to clearly articulate the experience from the patient's perspective. She was a true advocate for our patients, highlighting stressful points in the journey, from her own personal experiences, which we as care providers might not have considered. I was humbled to see how passionate Kristen was about ensuring that we as a team understood the patient's perspective and took the correct steps to improve our delivery of care."*

- Sheri Goar, Nursing Education Specialist,  
UW Health at The American Center

## REDESIGNING THE INPATIENT MAGAZINE

PFAs from the UW Health PFAC were influential in designing a new and improved inpatient magazine to help patients and families navigate the hospital and access resources during their stay. The new magazine, which will be updated every six months, will replace the patient guides currently in rooms.

PFAs contributed to decisions about the content of the magazine, helping staff understand what patients and families need to know when they are in the hospital. The magazine is expected to be in the rooms by January 2017. “The PFAs really validated this project and always offered quality input,” says Shawn Arneson, Director of Guest Services. “They are a joy to work with!”



## PATIENT EXPERIENCE TRAINING: Radiology's future is bright!

Radiology Manager Melissa Post has a vision for how 350 radiology staff members should interact with patients and their families. She understands the importance of their brief encounters and how they can impact patients' health care experiences. With the help of her staff, she created a multiday festival themed, “*Our Future is So Bright*,” (complete with sunglasses and sugar cookies) to launch a new department-specific (radiology) patient survey. Festivities included a patient experience video recorded by a panel of Patient and Family Advisors – Eric Sarno, Mary Ann Johnson and Peggy Zimdars—and moderated by Sandy Salvo. This video became a mandatory computer-based training (CBT) for all radiology staff and used real-life examples to focus on ways that radiology staff can reduce anxiety and provide reassurance to patients that they are in good hands.

Staff comments about how they are incorporating the principles of patient and family-centered care included:

- **Connect.** *I take the time to introduce myself to patients and make them feel at ease.*
- **Slow down and listen.** *Just listen. Have the patient express his/her emotions and actively listen.*
- **Assure.** *Assure patients of their safety, being heard and your attentiveness to their needs.*
- *Treat your patients as family and listen to anything they have to say; be **compassionate**.*
- *When you listen, you can pick up on people's fear and anxiety, and then you can **help calm them**.*

Melissa was particularly pleased to read this comment from a participant, which speaks to the impact of this training: “I have learned it is better to work *with* the patient and his or her family rather than just working *on* the patient.”

## URGENT CARE IMPROVEMENTS

In June 2016, Brian Tisch, Urgent Care Manager, and Karil Walther, Director of Clinical Support, presented to the UW Health PFAC regarding improvements to Urgent Care. This visit, paired with constructive feedback from the PFAs, led to the following changes in Urgent Care:

- Beginning in December 2016, Urgent Care hours will run from 8am to 8pm on weekdays, and from 8am to 5pm on weekends and holidays. The schedule changes provide extra hours of access for our patients.
- Working to create a system to post clinic wait times on UW Health's website. Patients will then be able to see wait times at the Urgent Care clinics before leaving home and make informed decisions.

---

## NEW VIDEO EDUCATES PARENTS, PREPARES CHILDREN FOR IMAGING PROCEDURES

Members of the AFCH PFAC provided valuable input and guidance on a [new video](#) that aims to better prepare families for what it is like for a child to have an Magnetic resonance imaging (MRI) scan. Many parents were opting for their children to go through the MRI experience unsedated, however they didn't realize how loud and scary the MRI would be for their child, explains Lori Haack, MPH, SCT (ASCP), CPHQ.

The new preparation video provides a realistic view of what it is like and explains the process in child-friendly language and visuals. The PFAs suggested that the video also be made available in Spanish. Prior to this project, there was no standard information provided to patient families about what to expect during a child's MRI. The video is now shown to families on an iPad prior to the procedure. Feedback has been positive and plans are underway to share the video via MyChart as well.



## INTEGRATING BEHAVIORAL HEALTH SERVICES INTO PRIMARY CARE (PILOT)

In June 2016, as part of a larger effort to redesign behavioral health care, UW Health launched a pilot (test) of a new care model that seeks to integrate behavioral health services into primary care. PFAs from both the Psychiatry PFAC and Primary Care PFAC played a key role in advising leaders and staff on a patient- and family-centered approach to workflows and educational materials, including “Introducing the Team” handouts for patients.

The new care collaborative model leverages the skills and relationships of RN Care Coordinators, who partner with patients to help set goals and offer coaching for managing chronic conditions like diabetes and hypertension. Now these primary care-based nurses are receiving additional training to be able to provide patients with evidence-based tools and techniques to help treat depression, with oversight from a consulting psychiatrist and primary care physician. This model has been proven to address symptoms of depression twice as fast as usual care. Behavioral Health Care Coordinators are also being added to work with patients who have depression, but not diabetes and hypertension.

Project leaders Heather Huang, MD, Elizabeth Perry, MD, and Sarah Boeding say the PFAs’ input has been tremendously helpful. “We always learned something new from the PFAs. Even when we felt pretty confident of what patients might want or need, the PFAs always enlightened us and made suggestions for improvements that didn’t occur to us,” says Sarah.

---

## ENHANCING CARE FOR THOSE AFFECTED BY DEMENTIA

**By Suzanne Purvis, DNP, RN, GCNS-BC,  
Clinical Nurse Specialist, Geriatrics**

Having PFAs on the Dementia Workgroup has been crucial in adding the family’s point of view to our discussions. This is a new workgroup and they have set the tone for our work, helping to get us off to a good start.

PFAs Gary Spann, Carol Gillen, Susan Friedman-Hill and Alan Sweet are an important part of the work that is being rolled out to improve and individualize care for persons with dementia. Initial work includes collecting data, improving documentation, and better identifying those we care for with dementia so that care plans can be individualized. Our work group looks forward to exciting things to come.



# LEADERSHIP

## Effecting Positive Change Statewide

PFAs Cindy Herbst and Peggy Zimdars, along with Program Manager Sandy Salvo, have been serving for almost two years on a statewide collaborative organized through the Wisconsin Hospital Association (WHA) to promote patient and family-centered care (PFCC) practices across Wisconsin hospitals.

This work has included the development of a toolkit for those interested in starting a Patient and Family Advisory Council (PFAC) and a webinar series. The patient advisors on the committee also helped WHA prepare a video that explains why this work is important from a patient's perspective. WHA hospital members can access the video via the WHA Quality Center ([www.whaqualitycenter.org](http://www.whaqualitycenter.org)).

PFA Mary Ann Johnson assisted with educating other hospitals through panel discussions for the Pharmacy Society of Wisconsin and at the 2016 WHA Symposium on PFCC Practices. As an example of how PFAs can be instrumental in effecting system-wide changes, our Care Team Visit Initiative was highlighted twice in 2016 in a webinar presented by Ann Malec, Anne Mork, Dr. Rob Hoffman and PFAs Eric Sarno, Peggy Zimdars and Kristen Cassarini.

The result? The number of PFACs in Wisconsin tripled in one year!

---

## PFA HIGHLIGHTS

“Being a part of the Patient and Family Advisor Partnership Program has given me courage to use my voice as I advocate for my son while teaching me the importance of seeing health care from a provider's (nurse or doctor) perspective. I really have felt like my input has mattered. I am able to connect with other PFAs as they have shared their experiences of caring for their children. That connection has made me feel like I'm not alone. I'm grateful for that.”

- *Brianne Coffey, PFA*

“I suggested that a picture be connected to MyChart when I visit my doctor. Wow, was I surprised at my next visit when they asked for a picture!”

- *Lois Bence Ehlke, PFA*

“I think one of the things that sticks out as a highlight is the willingness of UW Health to truly listen and solicit ideas. Our PFAC group has lots of input to share. Striving for excellence in patient care is invaluable as a patient or caregiver. Great variety of guests. Thanks for all you do in making this partnership productive and meaningful.”

- *Deb Harman, PFA*



# PATIENT AND FAMILY ADVISORY COUNCILS (PFACS)

## 2016 Highlights

### American Family Children's Hospital (AFCH) PFAC

*Facilitators: Julie Auenson and Kathryn Murphy*

- Created a [pediatric patient-focused video](#) and website updates for AFCH's Surgical Department
- Suggested design ideas and themes for AFCH's 7<sup>th</sup> floor expansion
- Requested installation of additional changing stations in bathrooms to accommodate older and larger special needs patients

### AFCH Youth Advisory Council (YAC)

*Facilitators: Heather Burgus and Callie Helfrich*

- Provided input and helped to create a new inpatient menu
- Featured one of the YAC members in a video to help prepare patients and families coming to AFCH for surgery
- Developed a transition plan for an online/media forum to make the opportunity to be a part of the council more easily accessible to patients

### Breast Center PFAC

*Co-Chairs: Gillian Schroeder, Mary Pat Berry, PFA, and Kim Lockwood, PFA*

- Reviewed and recommended adoption of Health Dialog Breast Cancer Decision Aid for new breast cancer patients to prepare for a shared decision-making conversation with the breast surgeon
- Reviewed and recommended adoption of the Dignicaps system to prevent chemotherapy related alopecia (hair loss)
- Reviewed clinical trial accruals and patients' perspectives

### CAC PFAC

*Co-Chairs: Allison Kelly and Michael Stacy, PFA*

- Welcomed two new PFAs and a new staff liaison
- Provided feedback on statewide action planning group and Comprehensive Care Program clinical services
- Planned the Fourth Friday Forum learning sessions

### Heart, Vascular and Thoracic PFAC

*Facilitator: Mary Francois*

- Held kickoff meeting and shared patient experiences
- Reviewed Health Facts For You with Patient Education Coordinator
- Arranged for heart failure physician to attend January meeting

### MyChart PFAC

*Co-chairs: Megan Jarosinski & Dr. Jon Keevil*

- Provided input on using MyChart as recruitment tool for research participants
- Contributed to child/teen MyChart access
- Contributed to expansion of proxy for teens

### Northeast Family Practice Medical Center PFAC

*Co-chairs: Susan Golz, Julie Kurt and Nicole Ledger, PFA*

- Discussed health and wellness needs of patients
- Conversated with new clinic manager, Rachel Nalwa
- Planned for member recruitment efforts

### Oncology PFAC

*Co-chairs: Kim Brandt, Kendra O'Connell and Marc Korobkin, PFA*

- Discussed UW Carbone Cancer Center health psychology and distress thermometer
- Provided patient perspectives on clinical trials
- Contributed to patient education on chemotherapy safety processes

### Primary Care PFAC

*Facilitators: Teri Helmke and Sandy Ehle*

- Updated on Complex Case Management Program
- Contributed to patient photo project in Health Link
- Provided input on provider departure letters

### Psychiatry PFAC

*Co-chairs: Lisa McGuffey, PhD, and Emily Comstock, PFA*

- Communicated with UW School of Medicine and Public Health Dean Robert Golden, MD, regarding the recommendation to increase resources for medical student training in psychiatry to address the shortage of psychiatric professionals; these suggestions are being considered in medical student curriculum development
- Collaborated with staff in developing the plan to integrate behavioral health services into primary care to increase access to mental health care
- Created messaging for digital signage designed to reduce stigma, inform patients about mental health services and advocate for the inclusion of LGBTQ population, including an "All Families Welcome" slide

### Transplant PFAC

*Co-chairs: Elizabeth Strutz and Brenda Juhlin, PFA*

- Provided input on how to communicate to patients who are not good candidates for transplant, including design of patient denial letter
- Revamped PFAC and added new members, now totaling 10 active members
- Helped plan the 50th anniversary/reunion events

### UW Health PFAC

*Co-chairs: Sandy Salvo and Mary Ann Johnson, PFA, and Cindy Herbst, PFA*

- Contributed to the redesign of Four Lakes Café at University Hospital
- Promoted Urgent Care Clinic expanded hours and wait time notifications
- Offered advice for Discharge Planning Tool and After-Hospital Care Plan

## PFAC SPOTLIGHT: TRANSPLANT

For the Transplant PFAC, 2016 was a year of celebration and progress. To celebrate the 50th anniversary of the UW Transplant Program, PFAs helped plan a formal gala, a patient and family reunion and a 5K walk/run.

PFAC members were instrumental in the success of the Patient Candidacy Improvement Work Group, helping to improve the communication process for patients who are candidates for transplant. PFAs participated in revising the letter sent to patients and creating additional education materials for patients to set clear expectations during the evaluation process.

PFA Herb Heneman played an integral role in developing the new Organ Donation and Transplant Service Line Business Plan, providing input from the patient perspective as goals and strategies are developed for the next three to five years. The Transplant PFAC continues to grow, revising its charter and welcoming four new members this year, bringing the total number of active PFAs on the committee to ten. Future projects include working to provide lower cost option pill boxes—vital tools for transplant patients with complex medication regimes—at the hospital pharmacy.

“The Transplant PFAC has become an essential part of our transplant service line. It’s a forum to hear directly from our patients and to collaborate on projects to improve the care we provide,” says, Elizabeth Strutz, Director of Transplant Operations. “It’s been an extremely valuable experience and I am thankful for the time and dedication from our PFAC members.”



### PFAC PARTNERSHIP PROGRAM BY THE NUMBERS

PFAs: 199 PFAs new in 2016: 40

#### Involvement across UW Health:

Standing Committees/Councils: 28

Search Committees: 2

Improvement Teams or Workgroups: 31

VOICES of UW Health Requests: 3

Webinars: 4

Videos for Staff Training: 2

Online Feedback/Surveys: 5

Other: 6 (MAGNET site interview/visit, WHA Patient Engagement Advisory Committee, WHA Conference, EPIC Conference, Care Team Visit Training Observations, UW Health Strategic Planning)

Focus Groups: 10

Facility Design/Redesign Workgroups: 2

# APPRECIATION

## PFAs Celebrated at Annual Appreciation Event

More than 100 Patient and Family Advisors (PFAs), guests and staff gathered in September 2016 to celebrate strides made in advancing UW Health's culture of patient and family-centered care through the PFA Partnership Program.

Chief Medical Officer Pete Newcomer, MD, served as emcee for the evening, which included the sharing of impact stories – highlighting how PFAs have helped to shape key initiatives, including care team visits; the integration of behavioral health services into primary care; integrative medicine pilot program; and the Hilary Grace Healing Garden, among others.

Lisa Grant, DO, internal medicine, delivered an inspiring keynote talking about the importance of mindfulness in health care delivery, as well as in our roles as patients, caregivers and PFAs.

PFAs received the “red carpet” treatment from Guest Services when they arrived for valet parking service. Guests enjoyed a buffet dinner, cake and door prizes, as they engaged in table discussions about their involvement and their vision for transforming health care for the better.



# GUIDING COUNCIL

The Guiding Council, comprised of both PFAs and staff, was chartered in 2015 to focus on continual improvement of the PFA Partnership Program and ensure that best practices related to partnering with PFAs are implemented throughout the organization.

The Guiding Council created the Vision Statement and Guiding Principles. It tracks performance metrics to measure the success of the program and the impact of the patient and family voice on organizational goals.

## Vision Statement

Working as **partners**, UW Health and Patient and Family Advisors seek to **transform** health care delivery by providing a forum for the patient's and family's voices to be **heard and understood**.

## Guiding Principles

Principles that guide this mutually beneficial partnership include:

**Values.** The core values identified by the leadership of UW Health – excellence, innovation, compassion, integrity, respect and accountability – guide the partners in their efforts to put patients and families at the center of their health care.

**Openness.** Partners openly discuss challenges to identify opportunities for improvement in the quality and safety of health care. Partners will cultivate a collaborative culture of honesty and candor to bring about systemic change.

**Inclusiveness.** Partners actively seek out diverse voices to understand the patient experience. Partners recognize that patients and families hold a variety of values and beliefs about quality of health care and the patient experience.

**Communication.** Partners communicate in ways that show respect for the knowledge,

## Guiding Council Members include:

Joe Guastella, PFA

Ann Massie-Nelson, PFA

Peggy Zimdars, PFA

Dianna Bower, Nurse Care Team Leader

Meg Chin, Program Director, Population Health Management

Sarah Esmond, Director, UW School of Medicine and Public Health

Dr. Rob Hoffman, Hospitalist, Medical Director, Patient Relations

Wendy Horton, Vice President, Performance Excellence and Internal Operations, The American Center

Ann Malec, Director, Medical Nursing

Anne Mork, Nurse Manager, Trauma and Life Support Center

Mia Morrisette, Program Coordinator, Nursing-Coordinated Care

Melissa Perkins, Nursing Patient Education Manager

Sandy Salvo, Program Manager, Patient- and Family-Centered Care

Helena Scherer-Jones, Director, Patient Relations and Patient/Family Partnerships

Deb Segersten, Nurse Manager, Surgical Trauma

Amy Smyth, Program Director for Performance Excellence, Transplant

Rebecca Spindler, Program Assistant, Patient- and Family-Centered Care

Executive Sponsor: Betsy Clough, Vice President, Quality and Patient Safety

experience and contributions of each participant. Communication is frequent, timely and comprehensible. Confidentiality will be respected.

**Education.** Partners advocate for incorporating patient- and family-centered care into all aspects of education for patients and their family or care providers. By promoting teaching, research, outreach and public service beyond the walls of the institution, partners help UW Health transform the future of health care.