



PATIENT AND FAMILY ADVISOR PARTNERSHIP PROGRAM

PROGRESS REPORT 2014





The Patient and Family Advisor Partnership Program has grown to include more than 150 patients and family members who are actively engaged in improvement efforts throughout UW Health.

Partnering with patients and families in our work is a critical part of creating a culture of patient- and family-centered care. At the center of UW Health's Strategic Plan is the goal of *providing a patient and family experience of compassion and excellent clinical quality.*

With strong leadership support, we have expanded our partnership to include Patient and Family Advisor (PFA) representatives on dozens of UW Health committees, councils and work groups. We are making great progress toward our vision of integrating patients and families into every aspect of our enterprise – from planning and policy-making, to facility design and experience improvements, to fully partnering with patients and families at every point of care.

Enclosed is a snapshot of progress made during calendar year 2014. Thank you for your support and contributions as we strive to advance patient- and family-centered care at UW Health.

ENHANCING THE DISCHARGE PROCESS - STEP BY STEP

“It was never the same experience twice. Sometimes it felt rushed; other times it felt delayed,” says PFA Irene Ekleberry, a member of the Discharge Collaborative, an interdisciplinary group working on standardization and other improvements.

The patient discharge process has long been an area in need of improvement with about half of UW Health inpatients and their families expressing dissatisfaction with their experience, according to patient satisfaction survey results.

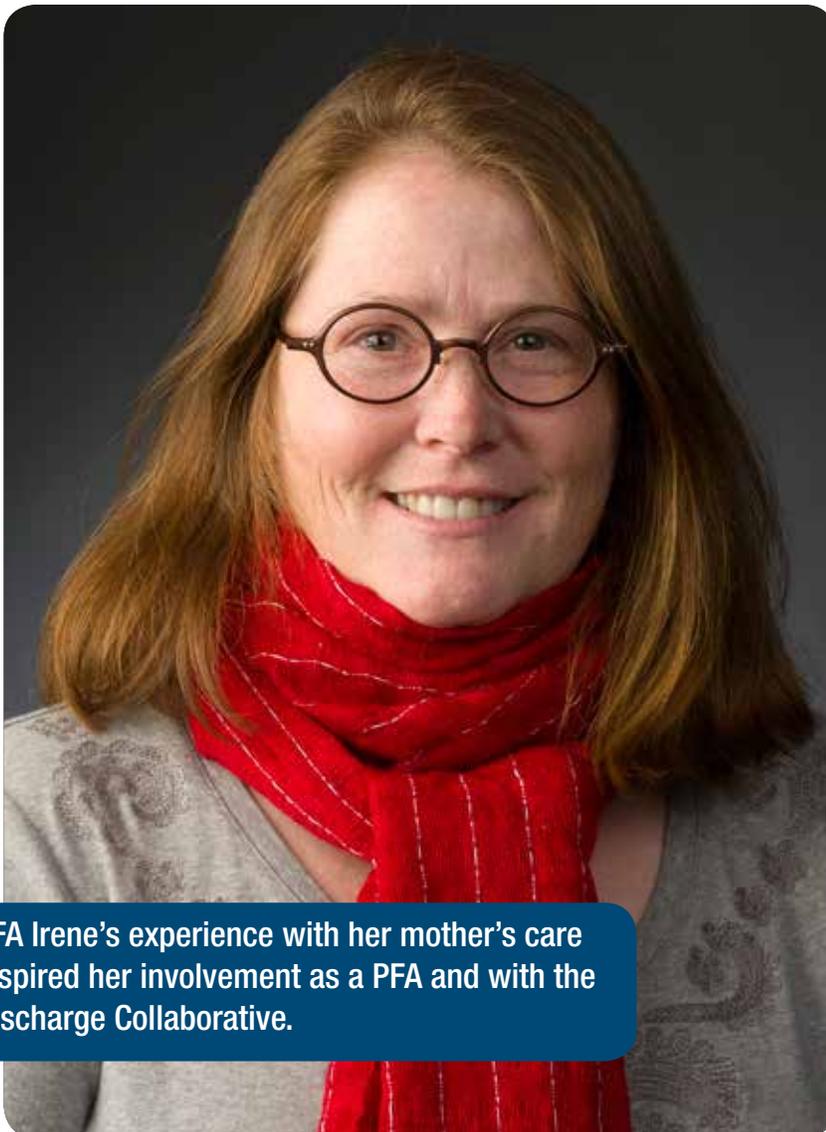
“In my experience, there was often little lead time, making it challenging for family members to be

there,” says PFA Peggy Zimdars, a Discharge Collaborative member. “It was difficult to know who to call, which appointments needed to be made and what to do as far as care instructions moving forward.”

Irene adds, “Just knowing what steps need to happen, when and in what order will be extremely helpful.”

In March 2014, after more than a year of planning, UW Health’s first standardized process for patient discharge began rolling out to all general care units. Designed to improve the patient and family experience, the new process includes entering, communicating and tracking an anticipated discharge date and time. Planning for discharge enables patients and families to make timely transportation arrangements, allows more time for patient education and reduces admission delays for incoming patients.

“The PFAs have been actively engaged in all Discharge Collaborative discussions and decisions, and they offered very helpful suggestions as we prepared for rollout,” says Ann Malec, MS, RN, Director, Medical Nursing. “PFA presence keeps our team focused on how the patient and/or family may be impacted by anything that we put into place; I can’t imagine our team without them. We value their input and consider them true partners.”



PFA Irene’s experience with her mother’s care inspired her involvement as a PFA and with the Discharge Collaborative.

PARTNERING WITH PATIENT AND FAMILIES TO REDUCE FALLS

“What happens in a split second can affect a patient and family for a lifetime,” says PFA Mary Ann Johnson. Mary Ann knows this firsthand from her father’s fall, which led to his decreased mobility, multiple surgeries and emotional decline.

A fall can cause major injury, prolong a hospital stay or even impact quality of life for the long-term. UW Health is making a concentrated effort to prevent falls in the hospital and is engaging patients and families every step of the way.

Mary Ann’s story, verbalized in her own words, was recorded and has been shared with clinicians and staff during training. “Nearly all of our nurses have heard Mary Ann’s story,” says Lyndsy Huser MSN, RN, ACNS-BC, Clinical Nurse Specialist, Nursing Quality and Safety. “Hearing this vivid, personal account has really put the issue of falls into perspective and helps keep prevention top of mind.”

During a hospital stay, some patients have a higher-than-normal risk of falling. This may be due to medicines, illness, surgery or treatments that can cause dizziness or make it difficult to get out of bed. Factors like crutches, bandages, or being connected to intravenous tubing can also affect mobility.

PFAs were convened for a focus group to learn how clinicians could connect better with patients and families to prevent falls. “Their input was really helpful. We still bring it up when making decisions and plans.”

Two PFAs, Mary Ann and Janet Stockhausen, joined a falls-related work group and have been attending monthly meetings, alongside staff. It



PFA Mary Ann’s story about her father’s fall is shared during staff training to personalize the importance of fall prevention efforts

was the PFAs’ idea to focus on what families can do to help prevent falls and they helped update the *Health Facts for You* publication to add the family role section. They also helped create a new *Health Facts for You* publication specifically on high fall risk information. PFAs also weighed in on the new high risk symbol (a leaf) and its design. And, they helped craft messages for the hospital’s e-signage system (LCD screens).

Patients, families and staff each play a role in falls prevention, and their collective efforts are working: the number of falls in the hospital last year (FY14) fell to the lowest level in six years. More work and continued vigilance is necessary, but significant progress is underway, certainly aided by the involvement of PFAs.

“I can’t say enough good things about working with PFAs,” says Lyndsy, “I tell as many people as I can about my experience and encourage them to partner with PFAs any chance they have.”

NEW GUIDELINES FOR SHARING LIFE-ALTERING INFORMATION WITH PEDIATRIC PATIENTS AND FAMILIES

“Sharing life-altering information unskillfully can have a lasting emotional effect on the patient and family and negatively impact their relationship with the care team,” says PFA Julie A. Plotkin. “These situations are stressful for patients and families, as well as for care team members who often have not been trained in how to do this well.”

When patient families at American Family Children’s Hospital let trusted providers know that they were dissatisfied with how information about their children was being shared, Sharon Frierdich, a pediatric hematology-oncology nurse practitioner, convened a work group that included PFA Julie, along with physicians, nurses, a social worker and a health psychologist.

The group’s efforts resulted in UW Health Clinical Practice Guidelines for sharing life-altering information, approved last July by UW Health’s Center for Clinical Knowledge Management. In creating these guidelines, to be used by all AFCH care teams, the group adapted a protocol from adult oncology known by the acronym, “SPIKES” (Setting, Perception, Invitation, Knowledge, Emotion, Summary/Strategy) for pediatric settings.

The steps include preparing for the meeting with the patient and the family, considering, among other things, whether the child should be present at the meeting. Other steps speak to interacting with the patient and the family, addressing emotional responses, summarizing information shared and next steps, and reflecting on whether the guidelines were used successfully.

Adam Wolfe, MD, PhD, created a one-hour training program on the guidelines. The workgroup created a pocket-size reference card so that a care team member may review the



PFA Julie’s experience as a parent of a patient shaped her input into the new clinical guidelines for sharing life-altering information with families and children.

guidelines before meeting with a patient and family, as well as a card that families can use to share life-altering information with their children.

Using pre- and post-training surveys, the group learned that the guidelines training increased the attendees’ assessment of their ability to share life-altering information in a more skillful and patient and family-centered way. A paper discussing the guidelines and the training was published in the September 2014 issue of the *Journal of Palliative Medicine*.

NATIONAL APPEARANCES

- PFA **Alan Sweet** presented at the American College of Health Care Executives Conference in Chicago in March 2014. Alan, alongside with Mark Hamilton, VP Ambulatory Services, and Flad architects, spoke about the key role PFAs played in designing UW Health at The American Center.
- PFA **Irene Ekleberry's** story was shared by Sue Sanford Ring, Vice President, Quality and Patient Safety, at the Patient Experience: Empathy + Innovation Summit in Cleveland in May 2014.
- PFA **Dawn Wavra** presented, alongside Program Manager Sandy Salvo, at an international conference hosted by the Institute of Patient- and Family-Centered Care, in Vancouver, British Columbia, Canada, in August 2014.
- PFA **Peggy Zimdars** and Helena Scherer-Jones, Director, Patient Resources and Patient/Family Partnerships, presented during an American Hospital Association Webinar in November 2014, highlighting national best practices for creating a culture of patient- and family-centered care.

INDUSTRY ACCOLADES

- 100 Best Hospitals for Patient Engagement, *U.S. News & World Report*
- Quest for Quality Citation of Merit for Patient and Family-Centered Care, McKesson-American Hospital Association
- *Better Together* exemplar award, Institute of Patient- and Family-Centered Care



PFAs taking part in a panel discussion during UW Health's Quality and Safety Week, October 2014.

IMPACT

"Our PFAs remind us why we must overcome barriers and make interdisciplinary rounding at the bedside with the patient and family a priority. The PFAs have shared compelling stories highlighting the negative impacts of not collaborating together as one cohesive team as well as positive examples of when things went well. These real life examples have kept our team focused on why the Interdisciplinary Model of Care (IMOC) is so important."

– Ann Malec, MS, RN, Director,
Medical Nursing

"Our PFA was invaluable in helping us determine metrics to pursue because of their impact on the patient experience. She advocated for measuring timeliness of services in calendar days and not only business days, reminding us, 'Patients don't stop worrying on the weekends.' Our quality dashboard has an appropriate mix of measures that include patient experience focused metrics due to the presence of our PFA."

– Gillian Schroeder,
Breast Center Program Director and Breast
Center Quality Metrics Project Team

"While the work of the Center for Clinical Knowledge Management Council is highly technical –debating practices that evolve into standards of care – we added PFAs to the Council to ensure that the voice of the patient is not lost in that discussion. When discussing clinical evidence, it's easy to forget that there are patients at the end of that debate, and we believe that including PFAs as active participants is helping all of us keep the end-game in the forefront of our minds."

– Lee Vermeulen, Director,
Clinical Knowledge Management Council

APPRECIATION

In October, PFAs were recognized for their many contributions during UW Health's second annual PFA appreciation event. "Blazing the Trail" was the theme of the celebration, which provided highlights of UW health's journey toward patient- and family-centered care, eloquently shared by PFAs Amy Whitehead, Julie Plotkin and Peggy Zimdars, as well as staff Sue Sanford-Ring and Helena Scherer-Jones. The celebration ended most memorably with a serenade by UW Hospital and Clinics CEO Ron Sliwinski who played "Happy Trails" on his accordion!



PFAS - BY THE NUMBERS

Total: 158 New in 2014: 78

Involvement across UW Health:

Standing Committees/Councils: 29

Improvement Teams or Workgroups: 17

Patient and Family Advisory Councils (PFACs): 12 *(see below)*

Conference/Retreat Presenters: 10

e-Advisor Projects: 8

Focus Groups: 8

Executive Search Committees: 4

Facility Design/Redesign Workgroups: 4

Staff Education/Presentations: 3

Research Projects: 3

Marketing Workgroups: 3

Other: 6 (including Quest for Quality application and site interviews, MAGNET site interviews, Diabetes Education Review, WHA Patient Engagement Advisory Committee, MyChart upgrade testing at EPIC, and University HealthSystems Consortium Project)

PATIENT AND FAMILY ADVISORY COUNCILS (PFACs)

UW Health Adult PFAC (est. 2006)
Co-Chairs: PFA Peggy Zimdars and Sandy Salvo

American Family Children's Hospital PFAC (est. 2006)
Facilitators: Julie Auenson and Kathryn Murphy

Breast Center PFAC (est. May 2014)
Co-Chairs: PFA Mary Pat Berry and Gillian Schroeder

Community Action Council PFAC (est. 2006, joined PFAC network in 2013)
Facilitator: Rachel Luzbetak

MyChart (est. Dec 2013)
Co-Chairs: Megan Jarosinski and Dr. Jon Keevil

Northeast Clinic PFAC (est. May 2014)
Facilitator Dr. Taryn Lawler

Oncology PFAC (est. April 2014)
Co-Chairs: PFA Shannon Lory and Kim Brandt

Primary Care PFAC (est. Nov 2011)
Facilitator: Teri Helmke

Primary Care Pediatric PFAC (est. Sept 2014)
Chair: Robin Valley-Massey

Psychiatry PFAC (est. Nov 2014)
Co-Chairs: Lisa McGuffey and Janet Bauer

Transplant PFAC (est. March 2013)
Co-Chairs: PFA Brenda Juhlin and Elizabeth Strutz

Yahara Clinic PFAC (est. February 2014, on hold as of August 2014)
Chair: Dr. Sandy Kamnetz