

## New Patient Family Advisory Councils at Sutter Health

September 2017 sees the exciting launch of five new Patient Family Advisory Councils across Sutter Health. The following locations are currently in the process of recruiting Patient Family Advisors for their newly formed councils:

- Hospice of the Valley, San Jose
- Modesto Memorial Medical Center
- Sutter Coast Hospital, Crescent City
- Sutter Tracy Community Hospital
- Sutter East Bay Medical Foundation

Patients and family members who are interested in joining these councils can learn more and fill out a referral on our website:

[www.sutterhealth.org/for-patients/patient-advisory-council](http://www.sutterhealth.org/for-patients/patient-advisory-council)

## Sutter Roseville Medical Center Celebrates PFAC First Anniversary

On September 1, 2017 Sutter Roseville Medical Center (SRMC) celebrated the one year anniversary of the creation of the Patient Family Advisory Council (PFAC). The PFAC group (now 17 members strong) gathered and celebrated with lunch and delicious cupcakes. The Patient Family Advisors shared stories about their favorite projects and how they feel they are really helping to make changes that will benefit the patients and families served at SRMC.



*SRMC Patient Family Advisors & Staff*



## Patient Family Advisor Summit

**October 24, 2017, 9am – 3pm  
Fairfield, CA**

The Patient Family Advisor Summit is a learning and networking opportunity for all Sutter Health Patient Family Advisors (PFAs).

All PFAs and council leads are welcome to attend. RSVP to Morgan Horwood by September 30<sup>th</sup> as space is limited.

**Meet other Sutter Health PFAs & leaders**

**Learning opportunity & Celebration**

**Storytelling & presentation training**

**Integrated healing arts**

**Health literacy & Lean**

**Mary Schramke, Patient Family Advisor,  
Palo Alto Medical Foundation,  
Sutter Health Patient Experience Council**

All of our Patient Family Advisors come to this role with a passion for improving the patient experience based on their experiences as patients and/or family members of patients. One such passionate and dedicated individual is Mary Schramke who has been a Patient Family Advisor at the Palo Alto Medical Foundation (PAMF) for two years. She has participated in many projects including the End of Life Option Act communication project and the PAMF Quality Improvement Steering Committee. Here is Mary's story:



"I have always enjoyed learning and sharing. I recently heard the phrase "without information, you suffer". For me, without the right information at the right time, you can suffer needlessly, especially in healthcare.

I have worked hard over the years to provide my aging parents the right information and support, so they could be the healthiest and happiest they could possibly be. Just like they did for me, one of seven kids, when I was growing up.

For my father, in the end, it was working to support his decision to die peacefully at home under hospice care.

For my mother, it is now to help oversee her care and well-being. In a flash, she moved from full independence into a frightening journey that included the emergency room, brain surgery, intensive care, long and arduous rehabilitation and now assisted living, where she struggles to keep life's forward momentum. All this can be traced back to a simple missed diagnosis in her cardiologist's office. I was there with her that day. I wonder, if I had only known to ask...

As a Patient Family Advisor, I partner with the staff at Sutter Health, learn new things, ask questions more intently and hopefully help the health care teams work smarter with patients and families to improve our healthcare.

Deep down I'm hoping that with this kind of work, every patient gets the right information at the right time and receives the right treatment we all strive for to improve our lives.

Through my work as a Sutter Patient Family Advisor, it is indeed better together."



*Mary's "North Star":  
Frank and Lorraine Schramke*

## Did You Know?

- Sutter Health's Patient and Family Advisory Councils have one goal: creating a nurturing and respectful care experience that involves listening, understanding and supportive guidance. Across Sutter Health, they have helped support **152 process improvement projects** aimed at helping the patient experience with **160 Patient Family Advisors** and over **1,800 hours** of service.
- Sutter Health is spreading the work of their Patient Family Advisors in two upcoming forums this fall:
  - [Planetree 2017 International Conference on Patient-Centered Care](#), Baltimore MD, October 15-18
  - [Hospital Quality Institute 2017 Annual Conference](#), Monterey CA, November 1 -3
  - [Next Generation Patient Experience Conference 2017](#), San Diego November 28-30

## neuroSHARE: Precision Care for Patients with MS

In early 2017, Sutter Health's Research, Development & Dissemination (RDD) group received funding for the "Precision Medicine for Multiple Sclerosis: Making it Work" project. The California Institute for the Advancement of Precision Medicine, plus partners from the private industry and Sutter Health Philanthropy, provided funding to improve the delivery of quality care for patients with MS. Dr. Walter Stewart, the Principal Investigator, teamed up with leading neurologists from UCSF to work toward the goal of providing patients receiving care in general neurology clinics at Sutter Health with the same level of care that they would receive from an MS specialist.

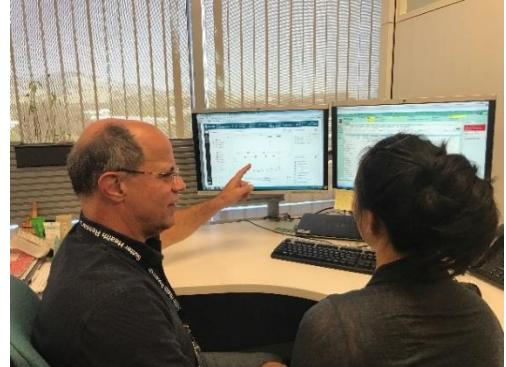
The term "Precision Medicine" might bring to mind images of scientists in white coats working in laboratories, but Dr. Stewart says, "Precision Medicine isn't just about the molecules of who we are, it's also about how precisely we measure and help improve the patient experience." Patient experience has been at the forefront of this project from the very beginning. With the help of the Office of Patient Experience, RDD identified more than 10 Patient Family Advisors who provided deep insight into their needs, as well as the challenges they face when seeking treatment for their MS.

The result of this collaboration is neuroSHARE, a web-based application used during neurology visits that brings together data reported by the patients with data from their electronic health record. The application (app) is meant to provide a comprehensive snapshot of how a patient is doing today, as well as their treatment history. The neuroSHARE app visualizes patients' disability status, current symptoms, disease trajectory, and MRI records all in relation to their prescribed treatments.

Program Manager Eileen Sabino-Laughlin shared, "In order for both patients and neurologists to adopt this new technology, it was essential for them to have a voice in the design." Patient Family Advisors provided feedback on all aspects of neuroSHARE that patients will see. That includes a patient-friendly questionnaire that allows patients to report symptoms, relapses, and their priorities for the upcoming visit; a redesigned After Visit Summary with actionable instructions; and even a mobile app RDD with pilot with 50 patients in 2018.

Ms. Sabino-Laughlin said, "I'm excited to see how Sutter patients respond to neuroSHARE. I'm hoping our inclusive approach to design, combined with the latest MS research, truly impacts the way our patients receive care."

The neuroSHARE app will launch in neurology clinics in Berkeley, Mountain View, and Palo Alto before the end of the year, with three additional sites to follow in early 2018. Dr. Stewart and his team are also planning to expand neuroSHARE to patients with migraines and movement disorders such as Parkinson's disease early next year. They plan to start recruiting Patient Family Advisors this fall.



*Dr. Stewart working with PFA*



*PFA's learning about the project*



*neuroSHARE project kick off*

**Interested in being a Patient Family Advisor and sharing your perspectives to help improve the Patient Experience?**

**Contact Morgan Horwood:**  
**916-305-7704**

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