



Stories of Patient & Family Advisors Collaborating on Research at Michigan Medicine

from



INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

Contributed by Marie Abraham, MA, Institute for Patient- and Family-Centered Care

Contact Email: mabraham@ipfcc.org

Background:

Michigan Medicine (formerly the University of Michigan Health System) began inviting patients and families to partner with them over twelve years ago. This came about after the wife of a critically injured patient chronicled the details of her husband's care over his 11 week hospitalization. She wrote as a way to help her remember important information about his care but she also wrote about her observations of how the experience could be improved. She shared her journal with senior leadership. They saw it as a valuable teaching tool for clinicians and staff and invited her to join the Patient Safety Committee becoming their first patient and family advisor.

Now, twelve years later, [Michigan Medicine](http://www.michiganmedicine.org) has over 400 patient and family advisors who serve on various onsite patient and family advisory councils, committees, and task forces. They also have over 800 e-advisors (advisors who work remotely) who review materials, share feedback, and respond to surveys. Given their reputation as one of the nation's leading research institutes, it is not surprising that patient and family advisors are asked to collaborate on research projects at Michigan Medicine.

Be Comfortable in the Hat You Are Wearing



Kori Jones, was the Program Manager for Children's, Women's, and Psychiatry Services at Michigan Medicine and coordinated their patient- and family-centered program for two years. Before starting this role, Kori was a family advisor and served on C.S. Mott Children's Hospital Patient and Family Advisory Council for over three years. In 2011, her youngest daughter, Ava, was born with a rare chromosome change which led her to get involved in health care. Initially, she went to researchers to ask if there was an interest in research related to her daughter's condition. Because it was such a rare occurrence, she found out that it was not a priority for research. After her initial disappointment, she decided to look for opportunities to add the patient and family voice to research design. She learned about the Patient-Centered Outcomes Research Institute (PCORI) and became involved as an early patient stakeholder reviewer of proposals and then later as a mentor for other patient stakeholder reviewers.

The Mott PFAC has been engaged in research through the Michigan Institute for Clinical & Health Research (MICHR), at the University of Michigan which provides assistance to researchers and helps them enhance their studies. Staff from MICHR have come to the Mott PFAC to get input on a variety of topics including improving study recruitment. Kori sees this as an ideal topic for patient and family advisors to provide feedback as they often have experience being asked for consent for their child to participate in a research study. They can easily look at recruitment brochures and tell researchers whether they would want to sign up to be a study participant or, if not, why not. Additionally, Kori has partnered with MICHR to include Patient and Family Advisors as Pilot-Grant-Program reviewers. As a result, MICHR has included patient centered criterion in their grant proposals and has trained and engaged patient/family reviewers in each cycle of their reviews.

As a parent, Kori understands that to be a strong advisor on a research project you have to recognize what you bring to the collaboration. Patient and family advisors experience the burden of an illness or a condition and have ideas about what burning questions they and other patients and families want answered. Also, advisors often understand the challenges of participating in a research study and can help researchers better design a study to reduce that burden. Advisors don't have to have knowledge and skills in research. Researchers bring that expertise. As Kori explains, "You as a patient or family member have to be comfortable with the very important hat that you are wearing. Anyone with broad perspective, good logic, and forward thinking will be a valuable partner."

Kori learned along the way that researchers should come to PFACs early in the process so that advisors can have an impact and are not viewed as a "rubber stamp" for a project. One recommendation is for PFACs to speak to researchers and ask them if any have ideas that they are thinking about so that as a proposal gets developed and research questions and methods get



refined, advisors can be part of the process. Another recommendation is that if a PFAC or individual advisors partner in a project, they should set the expectation that researchers commit to circling back with the PFAC and informing them of their progress and general findings and outcomes of a project. They should also tell advisors specifically how their participation made a difference. The leadership of a PFAC can set up a system that helps them document the proposals, studies, and researchers they have assisted so they can follow up when necessary.

Looking ahead, Kori suggests additional ways PFACs could collaborate in research. For instance, Mott's PFAC discussed developing clear language summaries of research findings for a newsletter so families could learn about research findings that may be helpful to them. Given the diverse population they serve at Michigan Medicine, advisors also talked about the need to translate research findings for patients and families for whom English is not their primary language.

Kori started her new position as the Program Director for Patient and Family-Centered Care in May 2017 at Beaumont Health in Michigan. She plans to continue her efforts to integrate the voice of patients and families in research.

Know You're Making a Difference



Georgiann Ziegler was diagnosed with chronic idiopathic pancreatitis in 2004 and since then she has spent between 50-100 days in the hospital each year. Four years ago she was asked to be a patient advisor. Because of her condition, she had retired from a much loved job as the Assistant to the Director of Civil Rights at United Auto Workers (UAW) International, and she thought that serving as a patient advisor would give her something meaningful to do. "Before this," Georgiann reflected, "I hadn't realized how important the patient voice is and that there was even an arena to use it."

She expected to be engaged as an advisor once a month to attend Patient and Family Advisory Council meetings but, like many enthusiastic advisors, her role grew quickly. She has served on the system-wide Patient, Family, Staff and Faculty Advisory Council (PFSAC) since it started in 2013. She also serves on a medical unit-based committee and the Learning Health Systems Steering committee.

She was invited by one of her physicians, Dr. Vineet Chopra to participate in the Michigan Appropriateness Guide for Intravenous Catheters (MAGIC) program. The project involved experts from all over the world who were conducting a systematic review of the literature to form guidelines. Georgiann has had multiple peripherally inserted central catheters (PICC) line placements over the years and also experienced a deep vein thrombosis from a PICC line. Dr. Chopra thought Georgiann could bring a different but vital perspective to the effort. He told her, "I would like you to sit at the table because you get it. You've been through the good and the bad with PICC lines."

For Georgiann the experience was exciting as well as educational. It was the first time she had ever sat in on something so intense, watching great minds work together, resolve differences of opinion, and come up with solutions. Dr. Chopra made sure that Georgiann played an active role in discussions, first by orienting her before the first meeting and then by asking for her input and stopping to explain more scientific or complicated information during the meetings. Georgiann felt that because of the highly scientific and specific nature of many of the discussions, there was a limit to how much she could participate. However, when she did share her perspective she believed that her contributions were significant and valued by the group.

Asking a patient advisor to serve on this panel was novel, but as Dr. Chopra stated in [an interview with Medscape](#), "We wanted to be different, first, because the evidence here is not very mature, there are very few randomized trials to guide us on our decision making and, second, because when there is uncertainty, it's imperative to have that conversation with the patient...A lot of the recommendations that we ended up with that were not evidence driven were really based on the patient being on our panel..."

Georgiann knew she had made a difference when she was asked to speak at a quarterly meeting for all the Michigan hospitals when they were discussing PICC lines. Georgiann still participates in the follow up efforts related to this project. More recently she has begun participating on a two-year PCORI-funded project, Improving Hospital Outcomes through Patient Engagement (i-HOPE) that is creating a prioritized list for research questions.

Georgiann shares the following advice to patient and family advisors who are considering partnering in a research projects:

- Depending on your role, it can be a big commitment and may be different than serving on a patient and family advisory council. Make sure that you have the time and are willing to give your time.
- In the beginning, you may feel like you're a foreigner in the meetings. Give it some time if you are trying to decide if it is a good fit.
- Don't be afraid to ask questions of those on the research team.
- Find the best person to connect with before or after meetings if you need more information in order to participate how you want.
- Be open and willing to share your views.
- Keep your fellow PFAC members updated about your participation and ask for their input to inform your efforts on research projects.
- Just because you are passionate about providing the patient or family voice, remember that sometimes silence is golden. Don't feel that you need to say something because you have been invited into the room. Recognize that in research projects, there will be times when you won't be participating in the discussions.



- If you are asked to participate on a research project as an advisor, I would encourage you to do it. Someone has seen something in you and believes your experience will make a difference to the project.

As a caution to researchers who are thinking about involving patient and family advisors, Georgiann suggests, “If you’re going to engage a patient then engage the patient. Don’t ask me to get involved in something if I am only going to be a check in a check box.” Patient and family advisors and PFACS can make researchers understand if they agree to participate, their participation has to be valued and meaningful.

Now, Georgiann is a big believer in patients and families sitting at every table. Before her role as an advisor and particularly as an advisor in research projects, she didn’t understand what goes into making changes. She just thought change happened. Now she is very appreciative of the length of time and hard work it takes to “move a pebble.” Like most patient and family advisors, she feels safer as a patient understanding the extraordinary efforts that go into making improvements in health care.

Paint a Fuller Picture for Researchers



Eleven years ago, when **Jim Pantela’s** wife was over six months pregnant, he was diagnosed with a late stage lung cancer. After his daughter was born and while he was in treatment, his daughter was admitted to the NICU because of seizures. At 21 days old she experienced a brain bleed. She is now 11 years old and has significant challenges. Jim retired from his position in management and consulting as his cancer and treatments prevent him from maintaining a career. This has not stopped him from diving very deeply into partnering in health care improvement and research.

He started to volunteer as an advisor at C.S. Mott and has worked on a variety of patient and family advisory councils but also was invited to serve on their Pediatric Ethics Council. After about a year, he was asked to join the Institutional Review Board (IRB) and serve as a liaison between the Ethics Council and the IRB. He started mainly in the IRB looking at pediatric studies but has since moved over to adult oncology. In Jim’s recollection, his participation in research “has mushroomed.” In addition to his efforts in pediatric and adult oncology at Michigan Medicine, he participates in IRBs and research review process for a variety of organizations including St. Joseph Mercy Ann Arbor, the VA, the National Cancer Institute, and PCORI.

Jim doesn’t deal with scientific aspects of studies with the exception of demanding, as any patient or family member would, that there is science and evidence behind the study. He believes that his role is making sure the safety of study participants is paramount and that there is honesty in the research process.



One achievement he is particularly proud of is the adoption of a three-tiered consent policy for research. He and other patient and family advisors along with researchers developed the policy based on the age of a child and brought them into the consent process in a developmentally appropriate manner. Jim and other parent advisors felt strongly that children and adolescents have the right to be informed and make decisions about whether or not they will participate in a study. Jim is now working to get this policy into national standards.

He finds that the researchers he works with are receptive to patient and family advisors. Jim recommends that advisors can most effectively communicate with researchers by telling them a story that is relevant to the research. As Jim has observed, “researchers can distill lessons learned from other studies and from the data.” When patients and families share their experiences, it dramatically paints a fuller picture of what it is like to live with their condition or illness and how research directly impacts them as a study participant or how they have benefited or not by the current research.

Jim plans to continue his activities and expand the influence of patient and family voices in research. “There are ways to allow illness and challenges to enhance your life,” states Jim. “I have no medical background but I get asked and invited and I do what I can. I see partnering in research as a way to keep learning. I enjoy what I do and I enjoy being able to give back.”

Support True Partnerships

Dr. Joyce Lee, [Doctor as Designer](#), is a pediatric endocrinologist at Michigan Medicine focusing mainly on diabetes. On a sabbatical, she delved into design thinking and more specifically participatory design where people who will be the end-users become co-creators in design solutions. She is committed to conducting her research in partnership with patients and families and has:

- Gone to the Mott PFAC to seek the participation of patient/caregivers in design thinking workshops and to solicit patient/caregiver ideas for student projects focused on development of health-related apps
- Worked with two teen advisors on a diabetes project focused on an app, that improved communication with their families related to their self-management (www.diabetesemoticons.com)
- Is working with a patient/caregiver-driven social media community that has developed their own do-it-yourself mobile applications for monitoring and managing diabetes

From her perspective as a researcher, she explains why involving patients and families is essential, “I can opine all I want, but I don’t live it, breathe it, and run the management of Type 1 diabetes every day. It really is a patient driven disease.” She believes that researchers have an important role in creating research programs that can support true partnership with patients and families across



the research continuum, from ideation to completion. To do this successfully, researchers must maintain open communication and transparency about the research process with patient and family advisors, to manage expectations from both sides of the partnership.

At **Michigan Medicine**, they are committed to partnerships with PFACs and advisors in research. What is clear from their example is:

- As patient and family advisors, you have a unique but essential role in research
- There is no requirement to have experience in medicine or research for you to be successful
- PFACs and advisors should set expectations with researchers that you are engaged early enough to make a difference in a project, are given enough information and encouragement to participate, and are kept updated about the impact of your contributions
- Sharing your lived experiences and being partnership-oriented will greatly help shape future research



To learn more about patients and families partnering in research, view the Institute for Patient- and Family-Centered Care's **Creating Sustainable Partnerships in Research Toolbox** at <http://ipfcc.org/bestpractices/sustainable-partnerships/index.html>