PORTAL is one of 29 networks in the National Patient-Centered Outcomes Research Network (PCORnet), which seeks to improve the nation’s capacity to conduct comparative effectiveness research by creating a large, representative network of care delivery systems and their data assets. The PORTAL network consists of Kaiser Permanente, HealthPartners, and Denver Health, and their 11 affiliated research centers.

Janice Tufte
Patient Engagement Council

Motivated by a deep-seated belief in the importance of “personal activation,” a lifelong interest in the medical field and her own medical challenges, Janice Tufte is ideally suited to serve as a PORTAL patient advocate.

Janice was one year old when her father was diagnosed with a malignant brain tumor, and three when he had experimental brain surgery. She vividly recalls the hospital bed set up in her parents’ bedroom and the many hours she spent by his side until he died six years later. Her mother cared for him during the day and worked as a pediatric nurse at night while a hired nurse looked after him. Even as a child, Janice helped out: “I bring it up now and then — the lessons learned by those of us who have the experience of caregiving as children.”

She has contended with medical issues herself, including multiple eye conditions, two eye surgeries, colon resection, diverticulitis and advancing arthritis. Several years ago, a visit to her physician because of pain in her upper gastrointestinal tract led to a colonoscopy that resulted in the removal of a tumor where “the high-grade dysplasia was on the way to full-blown cancer.”

Janice owns a small business, Hassanah Consulting (hassanah means “good deeds” in Arabic). Born and raised in Seattle, she is very active in the community. She founded and runs six projects addressing social determinants of health and serves on the Ecumenical Interreligious Advisory Council of Seattle University’s School of Theology and Ministry. She maintains and distributes a list of free, fun things to do in Seattle.

Janice is very involved in health-related advocacy and policy development organizations, including the Washington Health Care Authority’s Medicaid Title XIX Advisory Committee, SKC Health Care for the Homeless Governance Committees, and the Healthy Washington Coalition. She is a member of the American College of Physicians’ Citizens Guidelines Panel, and has been a patient research partner. She served as a Patient Co-Investigator on the PCORI-funded Learning to Integrate Neighborhoods with Clinical Care (LINCC) project undertaken by Group Health Research Institute (now Kaiser Permanente Washington Research Institute). In 2016, she co-authored a manuscript, “Learning to ‘Swim’ with the Experts: Experiences of Two Patient Co-Investigators for a Project Funded by the Patient-Centered Outcomes Research Institute,” in Permanente Medical Journal.

It was at PCORI’s annual meeting in 2016 that Janice was introduced to the PORTAL Patient Engagement Council. She had wanted to be more deeply involved with patient-physician communication and noticed that Group Health Cooperative was affiliated. As someone who believes in taking advantage of opportunities that present themselves, she researched PORTAL, reached out to ask about joining the PEC and became its first general (non-cohort-specific) member.

Summarizing her thoughts shortly after her appointment, Janice said: “I am looking forward to sharing the importance that the patient-partner voice brings to health research, our preferences, values and goals.”

Reference