Florence Kurttila has been deeply involved in cancer-related organizations for years working to empower those who can’t always speak for themselves. She encourages patients to assess their family history for cancer risk and look for clinical trials after diagnosis.

She seeks to help people who don’t know where to find help, what is available to them or how to ask for support, as well as those who accept a standard treatment as status quo and aren’t aware of clinical trials, new drugs or ways to help with discomfort.

Florence’s personal journey began with a lunch hour doctor’s appointment she’d made because of ongoing abdominal pain. She didn’t get back to work that day — or for many days. Following a CT scan, she was advised to admit herself to the hospital, and the next day she received the news that she had cancer. One day later, two-thirds of her colon was removed.

When she received her diagnosis, Florence said she was both mortified and convinced she would die. The tumor was the size of a grapefruit, but it had not spread. She had 26 weeks of chemotherapy, returning to work during that time while counting dry crackers as her new best friends. After she was diagnosed, her husband was diagnosed with late-stage colorectal cancer and died less than two months after diagnosis. Since her cancer and that of her husband, Florence says she has been intent on educating herself as well as others. Her advice for others is to persevere, have faith, rest when needed, and do their homework even if they don’t feel like it, as well as to ask questions, and search for “other ways, other treatments, other ideas.” She also suggests looking to family members, friends, and other survivors and patient advocates for support. She has now shown “no evidence of disease” (NED) for 18+ years.

“When someone asks you if they can do something for you, give them something to do!” she says. “They mean well, but sometimes don’t know how or what to say.” In addition to her work on the PORTAL Patient Engagement Council, Florence is a past board member of the California Colorectal Cancer Coalition and a member of several other organizations, advisory boards, and committees including the Fight Colorectal Cancer Research Advocacy Training and Support (RATS) program, the American Cancer Society, the Colon Cancer Alliance, and hospice care. She has worked on the California Dialogue on Cancer, 5-year Cancer Plan in the past and will be working on the Survivorship Portion of the Plan as it goes into its next 5-year planning cycle.

Florence is a member of the SWOG Cancer Research Network and volunteers as the gastrointestinal (GI) patient advocate on SWOG’s GI Committee.

As a research patient advocate, Florence regularly attends scientific meetings and has served as a grant reviewer. She has also been a peer navigator in clinical trial research. She earned Bachelor’s and Master’s Degrees in Human Resource Management and has an Associate’s Degree in Medical Secretarial Science. She held several positions for a biotech company for 23 years and is currently retired. She uses any spare time on grant reviews, curating clinical trials for Fight Colorectal Cancer, and participates as a Patient Advocate reviewer for several studies and proposals working with investigators who request a patient advocate on their committees.

Florence’s research advocacy spans a wide range of topics including biomarkers, genetics, survivorship, and new therapies. Her main interests are in colorectal and related cancers, as well as survivorship concerns and needs. Her advice to cancer patients and survivors is to ask questions, do research, become educated with your type of cancer, check out clinical trials and keep abreast of changes and new technologies. Above all, never, ever give up HOPE and share your story – you never know who you may help by doing that.

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.

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