# The Pace of Medicine

By Peg Ford

I was astonished at the pace at which the medical world functions when I went through my health crisis facing ovarian cancer 6 years ago. It was nothing compared to what I was to learn of the strides being made by the research and scientific world! I certainly had no idea I would be caught up in such speed when I became an advocate. I was slightly aware of how fast breakthroughs can change medicine, but I truly had no appreciation of how much, and how quickly, until my efforts and commitment to be an informed advocate took hold. Here are my reflections for the last half of 2012—a short summary of some of the activities!

In June 2012, a week before the US Supreme Court ruled on the Affordable Care Act, I was in Washington, DC, attending the 13th Annual Patient Congress of the Patient Advocate Foundation (PAF) as a member of the National Patient Advocate Foundation's (NPAF) volunteer Elite President's Council. After a full intense day of preparation, my fellow advocates and I, representing 39 states, called on Capitol Hill to visit with elected officials. We presented extremely important initiatives: Prescription Drug User Fee Act Reauthorization Drug Shortages and Breakthrough Therapies, Safeguarding the Patient Protection Provisions of Patient Protection Affordable Care Act, and Patients' Access to Treatments Act of 2012.

NPAF has been a leader in patient advocacy since 1996, focusing its activities on health policies determined to have the greatest impact on patients with chronic, debilitating, and life-threatening diseases to represent the majority of patients served by PAF, NPAF's companion organization (www.patientadvocate.org). More than 100,000 patients in all 50 states were provided case management assistance by PAF in 2011, and more than 5 million received online assistance.

Two weeks after my trip to DC, I traveled to the Dartmouth Institute for Health Policy & Clinical Practice at Dartmouth College in Hanover, New Hampshire, to participate as a patient advisor in a symposium at the Summer Institute for Informed Patient Choice entitled, "Measuring Shared Decision Making in Practice." Sessions and breakout groups discussed issues ranging from patient decision aids to identifying measurable outcomes. I also participated in a panel review on the last day to review and provide reactions to the priorities that the breakout groups developed over the course of the 2 prior days (http://tdi.dartmouth.edu).


Peg Ford with Kay Dickersin, PhD, Professor and Director, Center for Clinical Trials, Johns Hopkins Bloomberg School of Public Health, and Director, US Cochrane Center, at the Evidence-Based Guidelines Affecting Policy, Practice and Stakeholders conference.

A month later, in August, I again traveled to the DC area for an FDA Training Workshop, as I received an official appointment as a member of the Office of Special Health Issues (OSHI) FDA Patient Representative Program. As stated on the OSHI website, "The Patient Representative is responsible for providing the Food and Drug Administration (FDA) and the advisory committee the unique perspective of patients and family members directly affected by a serious or life-threatening disease." Further information can be found at the FDA's website www.fda.gov/ForConsumers/ByAudience/ForPatientAdvocates.

On October 7, 2012, at the opening dinner of the Scripps Cancer Center's 32nd Annual Oncology Nurses Symposium, I was thrilled to be the keynote speaker, addressing 268 attendees from across the country and around the world convened at the Hilton San Diego Resort in California. I spoke on the topic, "Ovarian Cancer—the Silent Killer! NOT ANYMORE!" However, I also took the opportunity to share not only the success of the Survivors Teaching Students (STS): Saving Women's Lives program of the Ovarian Cancer National Alliance in San Diego, but also the value of our nurses, as perceived by patients. My opening remarks were "I am not a medical professional or healthcare provider or researcher. I am a human being, patient, survivor, and advocate. I do not mean to imply the others mentioned are not human, but rather, I believe many are 'Angels in human form.' I hope to explain the ways in which I have arrived at this conclusion, and share about a grassroots movement happening across the country to give a voice and face to a matter of great urgency—ovarian cancer!" Cathleen Sugarman, RN, MSN, AOCNS, an oncology advanced practice nurse at Scripps Memorial Hospital in La Jolla, California, and course director, stated in her much-appreciated thank you note "You are a beacon of shining light. You inspired many nurses that evening with your enthusiasm for life and the work you have chosen as an ovarian cancer survivor."

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At the end of October, I attended the American Association for Cancer Research Fifth Annual Conference in San Diego on the Science of Cancer Health Disparities in racial/ethnic minorities and the medically underserved. Much insightful information was presented, from design and strategies for clinical trials for recruitment of diverse populations, to racial-ethnic disparities in patient-provider communication, as well as overall perceptions among adult cancer survivors of the quality of follow-up care (www.aacr.org).

In November, I attended the American Society of Clinical Oncology (ASCO) Quality Care Symposium, where the 200 anticipated attendees grew to more than 600 individuals attending this, the first meeting of its kind! It was heartwarming to hear the presentations and discussions focusing on issues vital to the patient community: communication, coordination, and shared decision making to involve and empower patients to participate in their own medical choices and care. The learning objectives included reviewing the evidence base in quality research, with a focus on comparative effectiveness studies and patient-centered outcomes research, as well as evaluating opportunities for further research to improve the quality of cancer care, including disparities research, communication, and decision-making research. It was a special pleasure to see that ASCO included a presentation by Michael L. Kappel on the patient perspective (http://quality2012.asco.org).

I was especially delighted to attend a presentation on ASCO's innovative new program, CancerLinQ. ASCO

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is taking a leadership role with its plan "to create a searchable knowledge bank—composed of information culled from millions of medical records provided by partner physicians that will yield specific, detailed information about presenting symptoms, courses of treatment, side effects, outcomes and more." This peer-reviewed, real-time, evidence-based healthcare technology not only will be at the fingertips of physicians and researchers, but also eventually will be a portal for patients to access! See www.conquercancerfoundation.org for information about this program.

The year 2012 included one more trip to the East Coast, this time to New York City in early December to attend the Evidence-Based Guidelines Affecting Policy, Practice and Stakeholders conference at the New York Academy of Medicine. Two full days focused on guidelines and involved all stakeholders, with breakout sessions covering such topics as how to develop pragmatic and trustworthy guidelines; how to close the gap between guidelines and clinical education; and how to incorporate consumers, including patients, in guideline development.

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Coupling this with facilitating presentations for the STS program, it certainly has been quite a hectic year! The Ovarian Cancer Advocacy Alliance of San Diego (OCAA), with help from our volunteer ovarian cancer survivors, completed 27 STS presentations to 672 attendees, including third-year medical students at the University of California San Diego School of Medicine, physician assistants and nurse practitioners at Kaiser Permanente, and nursing students at 10 schools of nursing in San Diego County.

Oh yes, 2013 is already kicking it up a notch with our announcement of a companion program for OCAA: HEAR (H: Hope, E: Experiences, A: Awareness, R: Risks), a community outreach program developed for civic organizations. "If Only I Knew Then, What I Know Now!" is the title of the new presentation by ovarian cancer survivors, who share their personal stories to increase individuals' awareness of the symptoms and risk factors of ovarian cancer to help empower women to be aware of their bodies and help spread the word about ovarian cancer awareness throughout the general public in San Diego County. In addition, I will be attending the Gynecologic Oncology Group 86th Semi-Annual Meeting and MD Anderson Cancer Center's 15th International Symposium on Anti-Angiogenic Therapy, as well as traveling to Portland, Oregon, in late January for the Summit Regional Meeting of NPAF's Elite President's Council to

participate in developing our Action Plan for legislative issues for 2013.

After having attended the Salzburg Global Seminar on "The Greatest Untapped Resource in Healthcare? Informing and Involving Patients in Decisions about Their Medical Care" in Austria in December 2010—where 58 people from 18 countries fashioned "The Salzburg Statement on Shared Decision Making," calling on "patients and clinicians to work together to be co-producers of health"—I have a renewed sense of hope for a paradigm shift in healthcare. I sense that 2013 will provide ample opportunities for what I consider to be the great honor of witnessing more of this movement in which patients will play an increasingly active role, along with their providers, in their medical choices and care. ("The Salzburg Statement on Shared Decision Making" was published in the September 2011 issue of *The Oncology Nurse-APN/PA*. Please go to http://www.theoncologynurse.com/ to access the article.)

Happy New Year! ●

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