

ASCO Affiliate Health Member Peg Ford: A Journey from Patient to Patient Advocate

Peg Ford spent most of her adult life on the sidelines of Western medicine. As a child growing up in a working-class family in Canada, financial barriers made it difficult for her to access health care, and then, as an adult, several negative experiences sent her into the world of alternative medicine, which she perceived to be more patient focused. But in 2007, Ms. Ford was diagnosed with ovarian cancer and within days, she found herself immersed in the system she had once avoided, running between the offices of gynecologic oncologists, radiologists, and surgeons.



Peg Ford

During her year of treatment, which included a successful surgery and chemotherapy, Ms. Ford noticed that her views about Western medicine were shifting. Instead of doctors who dismissed her concerns, she was now encountering caring nurses who stopped everything to make sure she was comfortable and talented surgeons who were determined to clear all the tumor margins. During that time, she also learned about the vast infrastructure of cancer research and how it forms the foundation of cancer treatment and, hopefully, cure. Soon, a thought started coalescing in her mind, eventually becoming a clear goal that would guide the next several years of her life: when she finished her treatment, she would give back to the health care system she had come to trust, and she would do so by becoming a patient advocate, defined by the National Cancer Institute (NCI) as someone who tries “to raise public awareness about important cancer issues, such as the need for cancer support services, education, and research,” among other tasks.

Today, Ms. Ford is a leading figure in the cancer advocacy world, having cofounded the Ovarian Cancer Alliance (OCA) of San Diego, which advocates on the national level on such initiatives as increasing research funding for the development of early-detection testing and improved health care practices. Under her leadership, the organization now runs a local branch of the Ovarian Cancer National Alliance’s program, Survivors Teaching Students: Saving Women’s Lives (STS). The program brings survivors of ovarian cancer into classrooms to share their experiences with medical and nursing students and veteran health care professionals, thus shedding light on the unique patient perspective. As of December 2013, STS had facilitated interaction of ovarian cancer survivors with more than 1,767 medical professionals at numerous institutions across the San Diego area.

ASCO’s Support for Patient Advocates

As a patient advocate, Ms. Ford plac-

es special emphasis on strengthening research funding, an endeavor that requires a strong understanding of current scientific developments in ovarian cancer. For this reason, she views the opportunity to attend ASCO’s Annual Meetings as an invaluable educational and networking experience. As the recipient of an ASCO Patient Advocate Scholarship—a program of the Conquer Cancer Foundation—she has been able to attend the 2010, 2011, and 2013 Annual Meetings.

“To say I see the importance of attending ASCO’s Annual Meetings is an understatement,” Ms. Ford said in an interview with *ASCO Daily News*. “These meetings not only broaden my understanding of the realm of science and the challenges facing the scientific world, but [they] open my eyes to the necessity of including the voices of survivors in the research discussion.”

Casting a Wider Membership Net

The Affiliated Health Professional category was created in 2005, but historically only a very few people met its criteria for membership. For example, patient advocates were eligible only if they were CEOs or Executive Directors of “nationally or internationally recognized groups.” However, numerous patient advocates expressed their concern over these criteria to the ASCO Membership Committee, prompting the committee in 2013 to open up membership to personnel who have leadership roles in patient advocacy, research, or policy, or who provide programs, services, information, and

support for people with cancer.

“Patient advocates play such important roles in supporting those living with cancer through raising public awareness of the disease, advancing cancer research, improving quality of care, as well as through tackling regulatory issues affecting cancer research and treatment,” said Membership Committee Chair, Tessa Cigler, MD, MPH. “The Membership Committee is so pleased to be able to welcome patient advocates as ASCO members, a change that furthers our abil-

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ity to work together to improve the life of each person living with cancer.”

Ms. Ford felt compelled to join ASCO for several reasons: “I wanted to show support to ASCO as an advocate. I also wanted to receive current information on advances and important findings affecting cancer research, and I wanted to hopefully collaborate with other professionals in order to expand the roles played by patient advocates in ASCO’s affairs.”

The Value of Networking

At the 2010 conference, Ms. Ford was interviewed by the editorial manager of

The Oncology Nurse-APN/PA and was subsequently invited to write for one of the publication’s columns, “Through the Eyes of An Advocate.” In addition, Ms. Ford believes that her attendance at ASCO paved the way to her being accepted to the U.S. Federal Drug Administration (FDA) Patient Representative Program of the FDA Office of Health and Constituent Affairs and as a stakeholder reviewer in the merit review panel of the Patient Centered Outcomes Research Institute (PCORI). Both the FDA and PCORI programs seek to include patients’ voices when evaluating new research and treatments for serious diseases.

“I cannot thank ASCO enough for the programs and opportunities provided for advocates, as I would not have been able to attain the level of involvement

or influence without such support and interest.”

Ford’s work has also taken her into the international arena, as in 2010 when she attended the Salzburg Global Seminar and worked with other stakeholders to draft a statement about shared decision making between physicians and patients.

Ford continues to embrace her role as a patient advocate and is looking forward to the road ahead. At the time of her interview with *ASCO Daily News*, she had just been elected by NCI to be a patient advocate on their Ovarian Cancer Task Force. ●

ASCO-Sponsored Patient Advocacy Booth, Programs, Resources

ASCO offers programs for patient advocates to further encourage and enhance their participation in the Annual Meeting. At this year’s Meeting, more than 300 patient advocates are in attendance, representing more than 100 patient advocacy organizations.

The ASCO-Sponsored Patient Advocacy Booth (Booth 3005), near the entrance of the Oncology Professionals Hall, is designed to give 28 nonprofit patient advocacy organizations an opportunity to promote their programs, services, and resources to the professional oncology community. Established in 1992, this booth serves as a place where participants can display materials and where Meeting attendees and patient advocates can network and exchange information.

There are also nearly 30 additional patient advocacy organizations that exhibit at the ASCO Annual Meeting. Along with the ASCO-Sponsored Patient Advocacy Booth, these exhibits comprise the Patient Advocacy Pavilion of the Oncology Professionals Hall. For a list of all exhibiting organizations, visit am.asco.org/exhibits-information.

This year marks the 8th consecutive year that patient advocates have been invited to apply for a scholarship to attend the ASCO Annual Meeting. The Conquer Cancer Foundation Patient Advocate Scholarship Program is made possible through generous grants from Bristol-

Myers Squibb, Lilly, Millennium: The Takeda Oncology Company, and Teva Oncology. Scholarships help cover expenses related to travel, hotel, and registration, so that advocates may attend the scientific and educational sessions at the Annual Meeting and then return to their organizations and their communities to share



what they have learned from participating in various cancer advocacy activities.

Research Review Sessions will be held in the Patient Advocate Lounge, today, 5:30PM-6:30 PM, S402. During these sessions, ASCO members review disease-specific topics presented at the Meeting, explain how the research is relevant to patients, and answer questions.

The following organizations are exhibiting at the 2014 ASCO Annual Meeting as part of the ASCO-Sponsored Patient Advocacy Booth.

- American Brain Tumor Association
- BAG IT
- Bladder Cancer Advocacy Network
- Bright Pink
- CancerCare
- Cancer Support Community
- Chris 4 Life Colon Cancer Foundation
- Colon Cancer Alliance
- Consano
- Debbie’s Dream Foundation: Curing Stomach Cancer
- Fight Colorectal Cancer
- Foundation for Women’s Cancer
- Free to Breathe
- Global Resource for Advancing Cancer Education
- Imerman Angels
- International Brain Tumour Alliance
- MyLifeline.org Cancer Foundation
- National Brain Tumor Society
- Nicki Leach Foundation
- Ovarian Cancer National Alliance
- Ovarian Cancer Research Fund
- Patient Access Network Foundation
- PearlPoint Cancer Support
- Prevent Cancer Foundation
- Support for People with Oral and Head and Neck Cancer
- Triage Cancer
- Ulman Cancer Fund for Young Adults
- Young Survival Coalition