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Clinical Trials Awareness, Confusion, and Clarity

By Peg Ford

After launching the Survivors Teaching Students program of the Ovarian Cancer National Alliance (OCNA) in 2008, and this year organizing the Ovarian Cancer Advocacy Alliance (OCAA) of San Diego, I have focused on 3 aspects of advocacy: 1) Effect change in the way medical doctors approach diagnosis and treatment of ovarian cancer by educating the medical community, patient organizations, and the community at large to achieve early diagnosis and improved treatment options; 2) Advance ovarian cancer research toward early diagnosis and improved quality of care; and 3) Address legislative issues that affect ovarian cancer care and research.

My first research effort was as a consumer reviewer for the Congressionally Directed Medical Research Program (CDMRP) of the Department of

Defense (DOD) for the Ovarian Cancer Research Program (OCRP). The DOD OCRP is the second-leading federal funding agency for ovarian cancer research in the United States. It was an amazing experience to participate in the first tier of evaluation, which is a scientific peer review of proposals measured against established criteria for determining scientific merit. From my perspective as an ovarian cancer survivor, I was able to give voice to how the research would impact the community while interacting with the scientists as an equal voting member. Without a doubt, it was an outstanding opportunity to learn about, as well as to support with my vote, pioneering research that demonstrated the quality and commitment of researchers in our country.

Thus began another phase of advocacy, legislative action to lobby Congress for funding to support ovarian cancer research. With the task of developing a screening test for ovarian cancer extremely important to my community, the funding for research is paramount. Without it, the devastatingly dismal statistic of a 45% 5-year survival rate will continue to haunt us. Having participated on the fiscal year 2009 and fiscal year 2010 DOD OCRP Peer Review Panels, I was able to share my experience and the importance of funding research with legislators. Attending OCNA's national conference in Washington, DC, for the past 4 years, I felt privileged to participate in their "Advocacy Day" each year, during which a group of survivors visited "the Hill" to call on members of Congress. I feel sharing our personal experiences made quite an impact in the meetings. This was just the beginning, as we continue the effort to represent the patient's voice locally.

Attending scientific conferences, including those of the American Society of Clinical Oncology, the American Association for Cancer Research, and the Gynecologic Oncology Group, as an advocate has given me insight on the complex and elusive challenges facing researchers. Yes, some advances have been made, but there is still, unfortunately, a long way to go. There is no way to know if a woman will get ovarian cancer. However, there are several factors that may increase the chances. For example, having tested positive for a genetic abnormality, *BRCA1* or *BRCA2*, can increase the chance that a woman will

get ovarian cancer. Having had breast, uterine, or colorectal cancer are also factors that could increase the risk of ovarian cancer. Also, having first-degree female family members (mother, sister, aunt, or grandmother on either a mother's or father's side) who have had ovarian cancer may increase the risk.

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Another vital factor is clinical trials. I knew virtually nothing about them—how important they are to research. What I did hear from researchers at the conferences was the need for more patients to participate. Why was this not happening? Why did I know so little about them? Initially I thought it was because my personal involvement with Western medicine was quite limited prior to my health crisis with ovarian cancer in 2007. But, I was in for a surprise. Desiring to increase my knowledge and awareness of cancer clinical trials, I started a new search. The statistics proved I was not alone, as less than 3% of all adults with cancer take part in clinical trials. Participation is even less among patients from racial and ethnic minority groups, those who are over 65, or those with low income. For all groups, there is a major lack of knowledge about cancer clinical trials—few people know about them. I also think that the average person does not realize the link between evidence-based medicine and clinical trials. I know I did not. Participation in clinical trials is essential to continuing to see advances in cancer treatment, but with so little participation, overall progress is slow. With this new understanding, how could I assist in a solution by advocating for cancer clinical trials in my community?

My search proved instructive, as I recently participated in an educational program provided by the California Ovarian Cancer Awareness Program (COCAP) (www.calovarian.ning.com) to strengthen the capacity of ovarian cancer advocates to encourage wider

clinical trials participation by women diagnosed with ovarian cancer. The training was conducted by the Education Network to Advance Cancer Clinical Trials (ENACCT) (www.enacct.org). ENACCT is the only national organization devoted solely to evidence-based, community-centered approaches to cancer clinical trials education. Its mission is to improve access to cancer clinical trials through education and collaboration with communities, healthcare providers, and research staff. Specifically, the Community Leader Training Program empowers community members to spread the message about the importance of cancer clinical trials to their peers in brief presentations with a call to action to "spread the word." I found the training intense, educational, and thorough in preparation to inform people in my community of this important option in cancer treatment and care. See the box for a list of resources.

As well, the current issue surrounding drug shortages is weighing heavily on people's minds. Researching and participating in webinars about this issue from the FDA, OCNA, and others is also important. The Executive Order, signed by the president on October 31, 2011, is only one step in addressing the widespread issue of drug shortages. The Executive Order does not change any law, but it directs the FDA to use existing powers to reduce the impact and duration of shortages. This problem, however, is not a simple one. An article by Jim Koeller in the October 2011 issue of *The Oncology Pharmacist*, "Will Anybody Be Making Cancer Drugs in the Future?," sheds some light on important factors in this matter.

Yes, we have challenges, but as a research advocate, I am becoming fully aware of the importance of clinical trials and, in particular, ovarian cancer clinical trials in the effort to eradicate this lethal gynecologic cancer and other cancers. Research is the only avenue where a potential screening test for ovarian cancer will emerge, and clinical trials are the avenue to bring this life-saving result to reality. Reaching out to inform patients and other individuals of the importance of clinical trials is one way I envision patient advocates as the bridge between the patient community and the scientific/medical world, working hand-in-hand to advance research and impact changes to better serve both communities. ●

Resources for clinical trials

- Cancer Information Service
1-800-4-CANCER
(www.cancer.gov)
- American Cancer Society
1-800-ACS-2345
(www.cancer.org)
- Ovarian Cancer National Alliance Clinical Trials Matching Service
1-800-535-1682
(<http://www.ovariancancer.org/clinical-trials/find-a-clinical-trial/>)

Patient resources

- Patient Advocate Foundation (PAF)
1-800-562-5274
(www.patientadvocate.org)
- Cancer Legal Resource Center
1-866-999-DRLC (3752)