

HOW PATIENTS CAN ADVOCATE FOR EVIDENCED-BASED RESEARCH

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OVARIAN CANCER ALLIANCE OF SAN DIEGO

As an 11+ year ovarian cancer survivor, my personal research into this deadly disease increased my awareness of the necessity to get involved and the urge to encourage others to engage in advocacy. Only through research could a screening test for the early detection of ovarian cancer, the most lethal gynecologic cancer, be developed to save more women's lives as well as advance cancer research and improve the quality of care for patients.



As a Cancer Research Advocate, I have been witness to the impact advocates have made over the last decade in regards to impacting research— whether that be from clinical trial design, reviewing prospective studies, or attending and participating as presenters at scientific conferences. I have also observed how research and medicine is moving to patient-centered outcomes and individual needs and preferences.

As evidence-based research is advancing from disease/organ specific to micro-environment, to molecular triggering precision/personalized medicine, the world of medicine is rapidly changing at a phenomenal pace requiring ALL stakeholders to be involved at all levels.

Today on national television, we often hear from medical doctors and healthcare providers on the importance for patients to be their own advocates in their healthcare. With the current trend of medical researchers approaching and paying attention to what the patient community envisions as vitally important, these successes get the community one step closer to acquiring funding and patient participation in clinical trials. There is a major shift occurring, escalating even more in the near future, as a tidal wave of need arrives for informed and involved advocates to represent and speak on behalf of the most important stakeholder: the patient!

Becoming an advocate seeking opportunities for training and experience requires commitment, time, and energy. Several national organizations have innovative training to prepare an individual to become an advocate:

- American Association for Clinical Research (AACR aacr.org) has an amazing training program, “AACR Scientist-Survivor Program;”
- American Society of Clinical Oncology (ASCO asco.org) offers sponsorships for advocates to attend their national conference;
- Research Advocacy Network (researchadvocacy.org) training program for advocates to advance patient-focused research for better patient care; and
- ProjectLead training program from the National Breast Cancer Coalition (NBCC breastcancerdeadline2020.org).

Having participated in these programs, I felt confident to apply to become an advocate in the FDA Patient Advocate Program and was selected to the NCI Ovarian Cancer Taskforce, both with ongoing training opportunities. Also, I have served on Steering Committees for Guidelines International Network/North America (GIN/NA) and Evidence-Based Research Network (EBRNetwork).

In addition to my position as President/Co-Founder, of the Ovarian Cancer Alliance of San Diego in my community, I am a member of the Community Advisory Board for UC San Diego Altman Clinical & Translational Research Institute (ACTRI) and Sanford-Burnham Prebys' Medical Discovery Research Institute Cancer Center (SPB).

Over the years I have attended, presented advocate posters, and been a speaker at several conferences, including internationally. Last year in April, attended the 3rd Annual Clinical Trials Patient Experience Summit in South San Francisco, by Panagora Pharma and Co-Host Genentech where themes covered included 1) How to include Patients in the Clinical Study Development Process; and 2) Designing Efficient and Effective Studies with the Patient at the Forefront.

As you can see, the demands for advocates are high and these examples are just the tip of the iceberg, with the dedicated efforts of the past influencing the impact the future will have. At this point in time most, unfortunately, are on a volunteer-basis, but perhaps in the not-too-distant future, as the value of advocates' participation becomes more and more necessary this, too, will change.

For more information on how to engage in cancer community advocacy efforts, visit <http://triagecancer.org/advocacy>.

For more information about engaging in legislative advocacy efforts, register for the webinar on July 25, 2018: <http://triagecancer.org/webinars>.

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Peg Ford, an 11+ ovarian cancer survivor, realized how lucky her cancer was diagnosed at early stage and how little awareness about this deadly disease, spurred her to take action to spread awareness and get early detection for all women! She is also ardently committed to her vision of patient advocates as the bridge between the patient community and the scientific/medical world, working hand-in-hand to impact changes to better serve both communities. She serves as a committee, advisory, editorial and peer review member on numerous panels and meetings to address issues affecting evidence-based research on local, state, national and international levels.