

Patient Advocate Corner

Ovarian Cancer National Alliance: Supporting Action, Education, and Awareness



Sherry Salway Black

By Sherry Salway Black

Three of four women with ovarian cancer are diagnosed in the late stages, when the chance of survival is not optimal. The story of the Ovarian Cancer National Alliance (OCNA; Washington, DC) can best be explained by these harrowing statistics. Ovarian cancer survivors want to change this prognosis and have banded

together to build a national movement to ensure a better future for other women diagnosed with this disease.

Betty Reiser, one of the Alliance's founders, created a program helping to increase a growing number of future physicians' understanding of ovarian cancer's symptoms and risk factors. In addition, these third-year medical students are gaining a perspective on survivors' real-life experiences and emotions—from the time of diagnosis through treatment and often into recurrence.

Reiser's idea has become the Alliance's signature program, Survivors Teaching Students: Saving Women's Lives. Survivors have taught the program to more than 11,000 medical students in more than a third of the 125 accredited US medical schools. As one medical student said, "I feel what I learned today will stay with me the rest of my life." The initiatives are focused on three interrelated activities: action, education, and awareness.

Alliance Initiatives

Action

Through the Alliance's advocacy arm, the OCNA, it is the only organization actively advocating for more research funding specifically for ovarian cancer. As a top National Cancer Institute (Bethesda, Maryland) official stated at the Alliance's last conference, "Until the Alliance was founded, research and technology for ovarian cancer was limited and had made minimal progress over the preceding 20 years. OCNA has substantially changed the research landscape for ovarian cancer, resulting in a dramatic increase in the amount and quality of cutting-edge research."

Later this year, the Alliance will launch the National Agenda for Ovarian Cancer. This national strategy will address priority action items to support the 172,000 ovarian cancer

patients and survivors and other women who are at higher risk of developing it. Specifically, it is a broad, comprehensive plan to advance ovarian cancer research and patient care well into the next decade. The platform will establish measurable goals to help research evolve, improve access to quality care, and affect legislation. The Alliance's 50-partner member organizations are actively participating in the plan's formation along with individual survivors like your patients, physicians, scientists, and policymakers.

Education

The Alliance provides the Clinical Trials Matching Service, powered by EmergingMed (New York, New York), to ensure that women and their physicians include clinical trials—a critical piece of the research continuum—in their treatment options. It is the one-stop shop for women traveling through an often difficult and confusing process.

Also, women are empowered through the Alliance's annual conferences. The 10th annual conference, Agenda for Action, will be held July 11 to 13, 2007, in Washington, DC. In addition to attending sessions on important quality-of-life issues for survivors, participants will learn about current research and expected breakthroughs, and how they can help increase research funding, improve health care access and patient care, and make their voices heard on Capitol Hill.

Awareness

The Alliance provides awareness materials for patients and the public. Fact sheets on topics ranging from genetics to clinical trials are available for download at www.ovariancancer.org. Symptoms cards and population-specific awareness cards are available for purchase online. The Web site itself has a wide variety of information for patients, survivors, and caregivers.

Your Involvement

The Alliance welcomes your involvement and hopes you will encourage your patients to take advantage of its resources or become involved with its programs.

Visit www.ovariancancer.org or e-mail ocna@ovariancancer.org for more information.

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