



Public Witness Testimony of
Susan Lowell Butler,
Executive Director, DC Cancer Consortium,
Founding Member of Ovarian Cancer National Alliance
on behalf of
Ovarian Cancer National Alliance

Mr. Chairman, Mr. Ranking Member, and distinguished Members of Congress, good morning, and thank you for inviting me to testify today.

I am Susan Lowell Butler, the executive director of the DC Cancer Consortium. I am also a co-founder of the Ovarian Cancer National Alliance, the national advocacy organization for ovarian cancer. I am a thirteen-year survivor of simultaneous breast and ovarian cancer - and I am here today to ask you to fund programs in the Labor-HHS and Education Appropriations Bill that will help combat ovarian cancer.

In considering this request, please consider the sobering statistics of this disease:

- Approximately 22,000 women were diagnosed with ovarian cancer each year – and about 15,000 women die annually from the disease. It is the fifth leading cause of cancer deaths among women – a statistic that has been true for many years;
- Fewer than 20 percent of women with ovarian cancer are diagnosed in the early stages of the disease, when survival is greatest. Only 45 percent of women diagnosed will survive more than five years;
- More than 70 percent of women will have at least one recurrence;
- When a recurrence happens within months after initial treatment, as is the case for many women, the cancer then responds to fewer and often less effective treatment options.

I am happy to say that so far, despite late diagnosis and the presence of another cancer, I have beaten the odds, and am pleased to be here more than 13 years after my diagnosis and one year after a recurrence. I wish I had more company.

There are three major programs that address ovarian cancer in this bill.

First is Johanna's Law: The Gynecologic Cancer Education and Awareness Act. Many of you have been vocal champions for this bill, and I thank you for your work. This program has been funded for the past two years, allowing the Centers for Disease Control and Prevention to begin a national awareness campaign about the signs and symptoms of gynecologic cancers. The law is named for Johanna Silver Gordon, who, like many women, had symptoms of ovarian

cancer which were missed by both her and her healthcare provider. Without a reliable early detection screen, our best hope for early detection is awareness among women and their health care providers of the signs and symptoms of ovarian cancer. On behalf of the thousands of women that experience symptoms of ovarian cancer, we ask that you appropriate \$10 million for this program for FY 2010.

But symptom awareness is just the beginning. We need better treatments for women who have this cancer, as well as real understanding of how it works in the body. We don't know enough about who's at risk, how this disease develops, how to detect it early, and how to keep it in remission. Without sufficient basic and translational research, we never will.

The NCI funds SPORE programs - Specialized Programs of Research Excellence -which are cross - institutional research programs – an important research collaboration. One of the SPOREs is run by the Gynecologic Oncology Group, which runs much-needed clinical trials on ovarian cancer. In Fiscal Year 2008, the NCI funded more than 500 research grants on ovarian cancer across a wide array of important issues. Keep this critical research going – and increase appropriations for the National Cancer Institute to \$6 billion for FY 2010.

Finally, the CDC runs the Ovarian Cancer Control Initiative, a research program that includes risk perception and screening for women at high risk for ovarian cancer; clinical practices in the follow up of ovarian masses; the relationship between symptoms and time to diagnosis; and tracking both incidence and surgical interventions of ovarian cancer. This research is of critical importance, and on behalf of the women and families who are touched by, or at risk of being touched by, ovarian cancer we request that you increase its funds to \$10 million for FY 2010.

Despite the grim statistics, the research you have funded over the years has brought progress for women with ovarian cancer. When I was diagnosed in 1995, the treatment options were relatively few, and harsh. Nonetheless, the clinical trial I was on at NCI saved my life. The good news is that today's first-line treatment allows most women to participate more fully in their lives throughout it – an immeasurable gift, I assure you. So on behalf of the entire ovarian cancer community – patients, family members, clinicians and researchers – we thank you for your leadership and support of federal programs that seek to reduce and prevent suffering from ovarian cancer. Thank you in advance for your support of these programs.