

# The Scoop From Rhonda's Club

Feb/March 2007

## President Bush Signs 'Johanna's Law' to Launch a National Gynecologic Awareness Campaign

*Sherry Salway Black*

President Bush has signed Johanna's Law, landmark legislation that authorizes development of a national gynecologic cancer awareness campaign. The federal campaign would educate American women and health professionals about the signs and symptoms of ovarian and other gynecologic cancers.

The President signed the bill on Friday, January 12. Both houses of Congress unanimously approved Johanna's Law: the Gynecologic Cancer Education and Awareness Act late last year.

Johanna's Law authorizes \$16.5 million over a three-year period to the U.S. Department of Health and Human Services for the awareness and education campaign. It is named for Johanna Silver Gordon, who died from ovarian cancer in 2000.

"This achievement is the result of the tireless work and dedication of all of our Congressional champions, the Society of Gynecologic Oncologists, and a far-reaching alliance of grassroots activists whose lives have been touched by gynecologic cancers," said Sherry Salway Black, executive director of the Ovarian Cancer National Alliance (OCNA). "The ovarian cancer community in particular has played a critical role in the passage of Johanna's Law through the Ovarian Cancer Action Network."

"This is an exciting development in our efforts to save women's lives through earlier detection of ovarian cancer," said Johanna's sister, Sheryl Silver, who conceived Johanna's Law and has worked tirelessly for its passage. "By educating the public about the risk factors and symptoms of gynecologic cancers, Johanna's Law will help women recognize potentially dangerous symptoms and seek appropriate medical attention sooner."

OCNA and other advocates now have another hurdle to overcome. Because Johanna's Law is an authorizing measure, it does not include any appropriations, so OCNA and other advocates will need to work to urge Congressional funding for the campaign.

### Plan to Attend

**March 26 at 6:30**

Please join us for our annual SGO Update and learn about key advancements in treatment and other topics related to survivorship.

**"SGO Update"**

**Jonathan Cosin, MD**

Section Director, Gynecologic Oncology, Washington Hospital Center

#### **Where:**

Lincoln Room (Lower Level)  
George Washington University Hospital  
900 23rd St. NW, Washington, D.C.  
At the Foggy Bottom Metro

#### **When:**

Monday, March 26, 2007  
6:30 PM- 8:00 PM

**Register:** (walk-ins welcome; registering helps us plan better)

Leave a message at 202-332-3358.

### Ready to Share Your Story??

Become an OGCC/Rhonda's Club volunteer and join our team as we implement the national OCNA Survivors Teaching Students program in the medical programs in our area.

Sharing stories is a powerful way for us to help inform the future doctors about the symptoms, treatment, and quality of life issues so very important to each of us.

The next **Teal Class** training session is forming, please call 703.346.3893 or email [cnaschin @ yahoo.com](mailto:cnaschin@yahoo.com).

### From the OGCC/Rhonda's Club Board:

While 2007 brings a new year, we pause to reflect on 2006. We rejoice in the passage and signature of Johanna's Bill and look forward to programs to get better awareness about the symptoms of ovarian and gynecologic cancers. We reflect in sadness that we have lost many fine women who struggled valiantly and serve as inspiration for our work. This includes our Board members Annie Shuma and Pam Solomon.

For 2007, we have new officers and added members to our Board. L. Paige Whitaker was elected Chair, Charlotte Naschinski, Secretary; and Clare Donelan-Dailey, Treasurer. Patricia A. Goldman, Fran Stolusky, and Michelle Hannah have joined the Board.

We have a full program of activities scheduled for 2007 and we need your help. Please consider volunteering for some of the on-going projects.

### 2007 Programs

There are lots of opportunities for you to get involved as a volunteer.

**Teal Class: Survivors Training Students.** Every 8 weeks, three volunteers meet with third year medical students at GW University Medical School and briefly tell their story. These stories provide a patient-oriented viewpoint that the students greatly appreciate. We will soon expand this program to additional medical and nursing schools. With a larger pool, our volunteers can anticipate sharing their time 2 or 3 times a year.

**Volunteers Needed:** Tell your story to medical students. **Add "Teal Class" to the voice mail or e-mail subject line so it can be handled promptly.**

**Survivor Education:** Our core program continues in 2007 with a full schedule of educational sessions. Volunteers can help us organize these sessions, mail materials, and/or participate in the planning process. **Add "Survivor Education" to the voice mail or e-mail subject line so it can be handled promptly.**

#### OGCC/Rhonda's Club Board

L. Paige Whitaker, Chair  
Clare Donelan-Dailey, Treasurer  
Susan Lowell Butler  
Patricia A. Goldman  
Michelle Hannah  
Mary Jackson Scroggins  
Ann M. Mason, Immediate Past Chair  
Charlotte Naschinski, RN, Secretary  
Fran Stolusky  
Susan Yaffee-Oziel

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### From the Ovarian Cancer National Alliance:

## SAVE THE DATE!

OCNA's 10<sup>th</sup> Annual Conference

A Decade of Action, a Future of Hope:

July 11 - 13, 2007

Washington, D.C.

### Public Symptom Awareness and Outreach:

Research shows that many women DO experience symptoms. Help us spread the word about symptom awareness.

- ⌘ **Health Fairs & Exhibits** – We are working with other partners to identify venues and opportunities. Volunteers are needed to 'staff the booth' for a few hours. **Add "Staff Exhibits" to the voice mail or e-mail subject line.**
- ⌘ **"Tell a Friend!"** Help us telling four friends; who then tell four friends. *etc.* we might just inspire a friend with symptoms to ask a doctor about her symptoms. **Contact us for postcards and symptom business cards to distribute.**

### It's easy to volunteer!

Consider volunteering for these various programs. To volunteer call 703-346-3893 or e-mail: [ann@cancer-ovarian.org](mailto:ann@cancer-ovarian.org). Add the program name to the e-mail subject line for more prompt handling (and to avoid the spam filter).

### Your support makes the difference!

## The Scoop From Rhonda's Club

Editor: Susan Lowell Butler  
Communications Committee:  
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The information contained in this newsletter mailing or any enclosure contained herein, should not be considered a substitute for the opinion of a qualified health care provider. OGCC/Rhonda's Club does not recommend or guarantee any product mentioned in this newsletter. Please use this information to assist you in obtaining further information and in making your own health care decisions.

## Clinical Trials & Research:

### Symptom Awareness Screening

Current standard of care does not recommend clinical screening tests (such as blood tests) for the general, symptom-free public. In an effort to better understand the role of specific symptoms for ovarian cancer, researcher Barbara Goff, Ph.D. and colleagues conducted a case-control study in women referred for pelvic/abdominal ultrasound. Women were asked to complete a survey of symptoms.

Symptoms that were associated significantly with ovarian cancer were pelvic/abdominal pain, urinary urgency/frequency, increased abdominal size/bloating, and difficulty eating/feeling full when they were present for less than 1 year and occurred more than 12 days per month.

A symptom index was considered positive if any of those 6 symptoms occurred more than 12 times per month but were present for less than 1 year. In the confirmatory sample, the index had a sensitivity of 56.7 for early-stage disease and 79.5% for advanced-stage disease. Specificity was 90% for women age more than 50 years and 86.7% for women age less than 50 years old.

Source: Goff, B.A., et al., 2007. Development of an Ovarian Cancer Symptom Index: Possibilities for Earlier Detection. *CANCER*. 109(2):221-227.

### Fertility Following Chemo

Often young women face the devastating loss of her reproductive capacity with the diagnosis of a gynecologic cancer. Researchers and Fertile Hope, a not for profit, are working together to retain options for parenthood. At Northwestern University researchers led by Teresa Woodruff, Ph.D, are developing a procedure to extract and mature eggs from frozen ovarian tissues to initiate pregnancies once cancer treatment has been completed. This procedure, when developed, could radically change the way infertility is viewed, reduce and eliminate embryo storage and provide better options for women who do not respond to hormonal therapy, " said Woodruff.

Source:

<http://www.sciencedaily.com/releases/2006/11/061130081517.htm>

### Quality of Life on IntraPeritoneal Treatment

Last year *The Scoop* reported the results of a Gynecologic Oncology Group (GOG) randomized phase III trial (GOG 172) that showed a significantly lengthened progression-free survival with intravenous (IV) paclitaxel plus intraperitoneal (IP) cisplatin and paclitaxel in optimal stage III epithelial ovarian cancer patients when compared to intravenously administered paclitaxel and cisplatin. In the February 1, 2007, issue of the *Journal of Clinical Oncology*, the GOG authors report on the quality of life outcomes for patient on IP versus IV therapy. The researchers concluded "that intraperitoneal chemotherapy is associated with significantly greater side effects during therapy than intravenous chemotherapy. However, it appears that neurotoxicity is the only side effect that remains significantly greater at 12 months following therapy for patients treated with intraperitoneal chemotherapy." Given the benefits of IP therapy, women will want to discuss the efficacy of treatment and the quality of life issues with her physician.

Source: Wenzel L, Huang H, Armstrong D, et al. 2007. Health-related quality of life during and after intraperitoneal versus intravenous chemotherapy for optimally debulked ovarian cancer: a Gynecologic Oncology Group study. *Journal of Clinical Oncology*. 25: 437-443.

## Risk Factors & Prevention

### ⌘ Eat your greens?

Researchers at Texas A&M University say they may have found a way to derive a cancer cure from foods like broccoli, cabbage, turnips and mustard greens. Using the natural compound, diindolylmethane (DIM) and similar indolyl compounds, researchers have altered DIM to make it more potent. In laboratory tests with rats and mice, the altered DIM inhibited the growth of breast, pancreatic, colon, bladder and ovarian cancer cells. Researcher Stephen Safe, Ph.D. says "One of the best parts is that this treatment appears to have minimal or no side effects; in the mice trials it just stops tumor growth. The hope now is that the patented chemicals can be developed into useful drugs for clinical trials and then be used for cancer treatment."

### ⌘ Exercise

Researchers from the Karolinska Institute in Sweden tracked the level of physical activity for 96,000 women from Norway and Sweden for over a decade. They found that the " risk of developing ovarian cancer was the same for women who were very physically active compared to women who did not move around too much."

<http://www.topcancernews.com/news/48/1/Exercise-does-not-lower-ovarian-cancer-risks>

### ⌘ Obesity

Researchers from Cedar Sinai reported that obesity affected survival rates, shortened the length of time to recurrence of the disease, and led to earlier death from the cancer than for women diagnosed at their ideal body weight. "This study is the first to identify weight as an independent factor in ovarian cancer in disease progression and overall survival, suggesting that there is an element in the fat tissue itself that influences the outcome of this disease in obese women," said Andrew Li, M.D.,

Source: Pavelka, J. et al., 2006. Effect of Obesity on Survival in Epithelial Ovarian Cancer. *Cancer*. 107(7):1520-1524.

**Remembrances**

OGCC/Rhonda's Club received donations in honor of **Annie Shuma, Lucy Schell, Marissa Irwin, Virginia Matthews, Rhonda Oziel** and **Ann Might**.

We also received celebratory donations honoring the birthdays of Annamarie Decarlo and Jack Oziel.

Ovarian Cancer Symptoms:

SEE YOUR DOCTOR if any of these symptoms persist for several weeks or recur frequently and are unusual for you:

- Constant bloating, abdominal pressure or discomfort
- Recurring nausea, indigestion, gas
- Frequent urinary urgency, constipation, diarrhea
- Abnormal bleeding, pain during intercourse
- Persistent, recurring fatigue
- Recurring backaches, abdominal or pelvic pain.

**History and Mission**

OGCC/Rhonda's Club was founded in 1997 by ovarian and gynecologic cancer survivors.

**OGCC/Rhonda's Club Goals**

1. All Washington area women with ovarian and related gynecologic cancers have access to supportive programs and information that improves the quality of their health decisions.
2. By 2020, 80 percent of ovarian cancer cases detected in the Greater Washington area will be diagnosed at an early stage.

**Mission**

OGCC/Rhonda's Club works to improve quality of life for women surviving cancer and to promote public awareness to improve earlier detection. Our programs include:

- Survivor Education**
- Teal Class—Survivors Teaching Students**
- Public Awareness & Outreach**
- Shape the Future.**

**I WANT TO HELP THE OGCC/RHONDA'S CLUB**

Enclosed please find my contribution:  
 \_\_\_\_\_ \$500    \_\_\_\_\_ \$250    \_\_\_\_\_ \$200    \_\_\_\_\_ \$150  
 \_\_\_\_\_ \$100    \_\_\_\_\_ \$ 50    \_\_\_\_\_ Other

(Optional) My gift is in

- memory of \_\_\_\_\_
- honors \_\_\_\_\_

*Please make checks payable to OGCC/Rhonda's Club, and mail to OGCC/Rhonda's Club, PO Box 12504, Arlington, VA 22219. We are a 501(c)(3) nonprofit organization. Your contribution is tax-deductible to the fullest extent of the law.*

Name \_\_\_\_\_  
 Address \_\_\_\_\_  
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 ZipCode \_\_\_\_\_ Phone \_\_\_\_\_  
 Email \_\_\_\_\_

- You may use the name \_\_\_\_\_ in any publicly written acknowledgement of contributors.

**Volunteer to participate in OGCC Programs!**

Consider spending a few hours working for our mutual success. Volunteering for these various programs is easy:

- ✂ Call 703-346-3893, leave a voice mail including the program name or
- ✂ Send an e-mail: ann@cancer-ovarian.org. Add the program name to the e-mail subject line to avoid the spam filter.

**The Scoop From Rhonda's Club**

Ovarian & Gynecologic Cancer Coalition/Rhonda's Club  
 P.O. Box 12504, Arlington VA 22219  
 (703) 346-3893  
 www.cancer-ovarian.org

OGCC/Rhonda's Club is a not-for-profit 501(c)(3) public charity.

We are founding and active partner-member of the Ovarian Cancer National Alliance.

Contributions are tax deductible to the fullest extent allowed by law.

*OGCC's tax id number is 54-2004729.*