

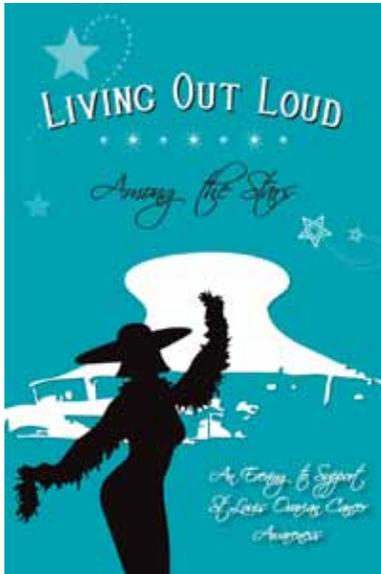


TEAL TALKS

MARCH 2010

Volume 2, Issue 1

Join Us for a Star-Filled Gala



Infusion nurses will be the earthly stars as St. Louis Ovarian Cancer Awareness gathers under the celestial stars at the James S. McDonnell Planetarium in Forest Park for SLOCA's annual dinner auction on Saturday, April 17.

At the event, Living Out Loud Among the Stars, SLOCA will honor 14 infusion nurses from the area's major gynecologic oncology centers. (See list.)

"When a woman is going through chemo, her oncology nurse is her life-line," says Karen Higano, president of SLOCA.

"These nurses dispense love, humor and practical advice even as they hook up the IVs and cover their patients with

warm blankets. We are pleased to recognize these nurses as stars among us."

In addition to honoring the nurses, SLOCA is preparing a slide show of the faces of ovarian cancer in the metro St. Louis area. We are collecting pictures of women patients and survivors of ovarian cancer and of those who have passed away from the disease.

The gala begins at 6:30 p.m. with an open bar, hors d'oeuvres and bidding on silent auction items on the lower level of the Planetarium. At 8 p.m., the silent auction will close and the party will move upstairs to a lovely sit-down dinner, the program and the live auction. Bob Hardcastle, host of the Money Talk radio program, will emcee.

This year, SLOCA will list in advance on its web site, www.sloca.org, many of the items to be auctioned. Stay tuned.

During the dinner, the winner of the "star" drawing will be treated to a view of the night sky that reflects the way it looked on a particular night chosen by the winner.

The dinner costs \$100 a person. The deadline for reservations is April 9. The annual dinner auction is SLOCA's premiere fund raiser. Last year's event netted more than \$25,000. The money goes toward SLOCA's awareness programs, patient support outreach, and grants for research concerning ovarian cancer.

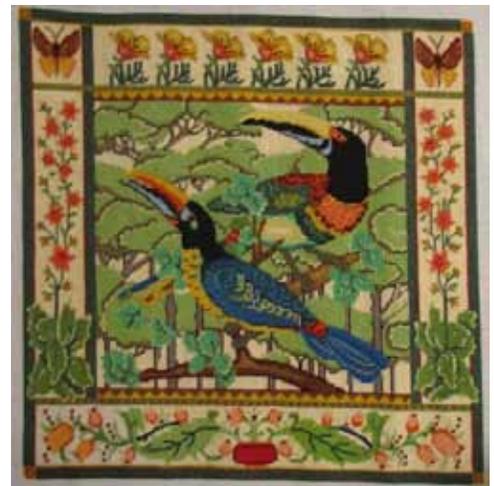
Contact us

To donate items for auction: Karen Higano, 314-680-9617, hoeflerin4@aol.com, before March 20.

For reservations: Grace Katzenberger, 314-849-3970, swtldy@swbell.net or mail the card on page 5. Reservation deadline: April 9.

To volunteer: Lisa Sienkiewicz, 314-882-1388, lisasienkiewicz@hotmail.com

Submit a photo: E-mail digital files of people touched by ovarian cancer to bethhudson715@yahoo.com before March 10. Include name, year of diagnosis and, if applicable, year of death.



This petit point of toucans, donated to board member Nancy Marron will be auctioned.

Honorees

Krystal Martin, Gina Bradford, Susan Rahn, Mary Stewart, Angie Holtgrave – all at Washington University OB/GYN Consultants at BJC.
Kim Benson and Danyelle Schuler – both at Women's Oncology Center in West County.
Nancy Larson, Tiffany Mersch and Chanelle Lomnick – all at Center for Women's Wellness and Fetal Health at Missouri Baptist Medical Center.

Ann McDonald, Chris Fairchild and Kristin Deshpande – all at St. Louis Gynecology and Oncology in Creve Coeur.

Carol Greenberg at SLUCare Department of OB/GYN at St. Mary's Health Center.

Survivors Teaching Students: Saving Women's Lives

The title may seem dramatic, but for the women who participate in this SLOCA speakers' program, saving women's lives is a very real goal.

Following the lead of a program begun in 2002 by the Ovarian Cancer National Alliance, SLOCA sends survivors of ovarian cancer into the classroom to tell their stories to medical students.

"We try to put a human face on this disease," says Jan Paul, the program's coordinator. "By doing that, we hope doctors and nurse-practitioners will remember our stories, recognize our symptoms and diagnose their patients at an early stage. That could very well save women's lives."

Oncology nurse Nancy Larson has trained dozens of speakers since the program began, and about 15 women currently participate. The survivors speak to third-year medical students from Washington University and St. Louis University, to resident doctors at St. John's Mercy Medical Center and to nurse-practitioner students at UM-St. Louis and St. Louis University. SLOCA wants to expand the program this year to include nursing students.

At each talk, Jan or Lisa Sienkiewicz facilitates. Four women tell the stories of their symptoms and how their disease was diagnosed. Each story is different, and each illustrates that ovarian cancer may be hard to detect but it's not silent. Each woman had very real symptoms, some of which were overlooked or mistakenly diagnosed as irritable bowel syndrome, bladder infection, menopause or even depression.

One woman has often recounted how she recognized her symptoms when she glanced at those listed on a bookmark distributed by SLOCA. Some were incontinent. Some found their clothes getting too



Four women told their stories on March 1 to third-year medical students from St. Louis University at St. Mary's Health Center. The speakers, standing from left to right, are Barbara Platzer, Saundy Templeton, Jan Paul and Joanne Henderson.

small even though they had not gained weight. Some lost weight without explanation.

The students learn that a pelvic exam should include the vagina and the rectum, and that symptoms should be considered in conjunction with a transvaginal ultrasound, CT scan and CA-125 blood test.

They also learn that while there are a dozen or more possible symptoms, nearly every woman diagnosed with ovarian cancer had at least one of these symptoms:

- Bloating
- Pelvic or abdominal pain
- Difficulty eating or feeling full quickly
- Changes in the frequency or

urgency to urinate

And they learn how to deliver the news to a patient in a way that offers her hope.

Judging from the evaluations the students return, the program is having an impact. Here's what some of them have said:

"It is powerful to put faces on a disease.

"The diagnosis seems less grim now.

"This was more memorable than book learning.

"This changes my future practice for the better.

"As a physician, it also gives me hope.

"It will now be on my radar.

"You realize that these diagnoses we give patients everyday really change their lives, and it's invaluable to look at patients as people, as moms, sisters, daughters."

That says it all.

If you are a survivor and want to volunteer as a speaker, call Jan at 314.749.2666 or e-mail her at janpaul@sbcglobal.net with a subject line of "Survivors Teaching Students."

SAVE THE DATES

April 17. Living Out Loud Among the Stars dinner-auction. Location: James S. McDonnell Planetarium in Forest Park.

May 22. 12th Annual Cancer Survivorship Walk. Benefits The Wellness Community of St. Louis. Location: Creve Coeur Park.

August 15. Ovarian Cancer Awareness Day at the Ballpark. Benefits SLOCA. Location: Busch Stadium, Cards vs. Cubs.

August 29. Rise & Shine for a Cure yoga event. Benefits SLOCA. Location: World's Fair Pavilion in Forest Park.

September 16-18. Trail Ride for Ovarian Cancer. Benefits SLOCA. Location: Katy Trail, Clinton, Mo., to St. Charles.

September 26. ROC Star 5K. Benefits research by Washington University at BJC. Location: Forest Park.

Fleece Angels Bring Comfort to Patients



Maggie Munaco (far right) pieced together this quilt from excess patches of fleece. With her, from left to right, are Kathy Murano, Barb Takavitz and Rose Ingraham.

By Kathy Murano

About every two months, laden with stuffed plastic bags, we deliver fleece blankets to the 13th floor of the Siteman Cancer Center for new patients in the gynecologic chemo unit.

The nurses always greet us with a smile. Often they immediately select a blanket and scurry off to a patient who truly needs one. When we leave, our bags are empty but our hearts are full.

Former patient Cindy Spencer started the Fleece Angel project five years ago after hearing about a similar program for children. Cindy thought, "Why not make fleece blankets for my friends at Barnes? It's always so cold in the treatment center, and everyone could use a little comfort there."

Cindy started by funding the project herself, taking blankets each time she went to treatment. Since Cindy passed away, her friends have continued the project in her memory. Hundreds of blankets have been donated since Cindy's inspiration. Friends, family, co-workers, neighbors, book clubs, church groups, Girl Scouts, patients, Barnes staff members and SLO-CA have contributed to this project.

A Fleece Angel gathering is busy and joyful as guests cut and tie the cheerful fleece fabrics. One friend summed it up best: "These blankets are stuffed animals for adults."

A quilt, sewn by Maggie Munaco from excess patches of Fleece Angel fabric, now hangs at the chemo infusions unit at Siteman. It represents the culmination of all those who have contributed or received comfort from this cause.

How you can help

1. Make a fleece blanket. It's simple. Purchase 1.25 yards of brightly patterned or colored fleece. Fold the fabric in half and cut a 5-inch square from each corner along the cut edge. Next, at 1-inch intervals along each cut edge, make a 5-inch cut from the edge toward the center. Unfold the fabric and knot each strip.
2. Donate money or fleece. Call or e-mail Barb Takavitz, 636.532.3033, barbtak@sbcglobal.net; Kathy Murano, 636.458.8875, fm1621@aol.com; or Rose Ingraham, 636.256.4771, roseingraham@aol.com.

DONATIONS

The following donations were made to SLOCA in January and February, 2010, in memory of:

Anne Marie Beckman

Darlene Whitlock

Sandra Bischof

Barbara Platzer

Kathy Covey

Marjory Barr

Lois Dinnius

Karen Arico

Lois & Leonard Spriggs

Eldwanda Kramer

Jill Myers

Ellen & Daniel Robert

Robert & Jeanette Albright

Mary Meyers

Co-workers at AT&T Services Inc.

Jan Lasky Platt

Joan & Stanley Hollander

Edda Prats

Dennis & Denise Bailey

Norman Ball

Karen Bayston

Jo Ann Bordeleau

Judy & Pete Boynton

Steve & Trudy Coffman

Thomas Colclasure

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Stephen & Karen Benedict

Rosanne Stockman-Block

Susan & Ty Thompson

Douglas Turner

Mary B. Visel

Frederick & Gisel Waide

Judith & Daniel Wesoloski

Linda Wickenhauser

A dear friend

Gail Stone's mother

Bob & Libby Stone

Craig Liddle's father

Bob & Libby Stone

IN MEMORIAM

It is with great sadness that we note the passing of three active SLOCA volunteers. All were extraordinarily effective speakers in SLOCA's program, Survivors Teaching Students: Saving Women's Lives. More importantly, all were our friends.



Sandra Bauer, a former county librarian, passed away on February 28, 2010, after a five-year battle with ovarian cancer. She often began her story by repeating the slogan, "Ovarian Cancer, It Whispers, So Listen." In 2005, Sandy recognized her symptoms among those listed on an ovarian cancer bookmark distributed at her branch library. Over the years, she endured several courses

of chemotherapy. She told her medical audiences that her disease was categorized as chronic, but added, "I do have quality in my life and wonderful family and friends. With their love and support I will face challenges of this disease."



Board member **Jacquelyn Morris** passed away on February 22, 2010, after a 3-year battle with epithelial ovarian cancer. Jackie was a tireless volunteer for SLOCA and a member of SLOCA's Board of Directors. A retired nurse, she staffed a booth for SLOCA at many health fairs each year. Perhaps

because of her medical training, medical students listened more attentively to her when she told the story of her diagnosis. We will miss her gentleness, her persistence, and her smile.



Susan Bober, a retired art teacher, passed away on October 24, 2009, after a 3-year fight with ovarian cancer. She and her sister, Beth Hudson, were featured speakers at SLOCA's 2009 Living Out Loud dinner auction. Sue was a frequent speaker to medical students, telling the story of her diagnosis and her experience with genetic testing. Sue also was an active participant in the GYN networking group at The Wellness

Community. Sue's discovery in May 2006 that she had late-stage ovarian cancer ultimately led to Beth's diagnosis of an earlier stage of ovarian cancer. Beth often says Sue saved her life. Unfortunately, Sue battled recurrences until she succumbed late last year. She faced setbacks and obstacles with spirit and aplomb, always signing her e-mails to friends, "Life Is Good."

ASK THE DOCTOR



Dr. Mutch

Patients often ask me, "Is my cancer hereditary? And will my children be affected?" Between 5 percent and 10 percent of ovarian cancers are hereditary in nature. The heralding signs of hereditary cancers are (1) early onset of the cancer and (2) multiple relatives with a cancer.

Early onset usually means the disease occurs before age 50, but that's not always the case. Sometimes hereditary disease may not present at early age. When it does, it is a very good predictor that the disease is hereditary -- and that should raise a red flag in any family. However, sometimes hereditary disease presents later in a patient's life as well.

There are tests available for inherited disease. Typically, we recommend testing only after a genetic counselor has discussed the risk with the patient and other interested family members.

We believe that it is important that patients understand the ramifications of a positive result as this will affect the whole family.

Also, we will keep the records so that if new information is discovered even years down the line we can contact the patient and let them know.

Anyone with ovarian cancer should ask her physician about genetic counseling and testing. Genetic counselors are on staff at most major cancer centers in the St. Louis area.

Have a question for Dr. Mutch that would interest other survivors, patients or caregivers? Send it to info@SLOCA.org for possible inclusion in a later newsletter. Direct questions about an individual's health to that patient's doctor.



Fight Like A Girl: SLOCA introduced a new T-shirt reading, Fight Like A Girl, at the Working Women's Survival Show in late February, and women eagerly snatched them up. The T-shirt is a cotton blend in a soft green with teal lettering and costs \$10. It comes in sizes from small to 2XL. Call Grace Katzenberger, 314-849-3970, to order one; postage and handling will be added.

CHECK IT OUT

St. Louis Ovarian Cancer Awareness offers information, support and fellowship. Go to www.sloca.org.

The Wellness Community of St. Louis has a support group, the Gynecological Cancer Networking Group, which meets the third Monday of each month at TWC's facility, 1058 Old Des Peres Road in Town & Country. For more information, go to <http://www.wellnesscommunitystl.org/>.

Together is a free support group for women affected by gynecologic cancer that meets each month at Barnes-Jewish Siteman Cancer Center, on the first floor at 660 South Euclid Avenue, St. Louis. The group meets on the first Wednesday of each month from 5 to 6:30 p.m. Call 314-362-4180 for more information.

The Ovarian Cancer National Alliance offers information about clinical trials, research funding, education and advocacy efforts on a national level. Go to www.ovariancancer.org/.

OCNA's web site also offers a personal Symptom Diary that was developed in cooperation with the Gynecologic Cancer Foundation to track persistency of symptoms over time. In addition, you can find an Interim Practice Guidance tool that outlines important steps your doctor may take to evaluate whether your symptoms may be ovarian cancer. Go to www.ovariancancer.org/diary.

The Women's Cancer Network web site provides a confidential assessment of your chance of developing ovarian cancer. Go

to www.wcn.org and click on "Am I at Risk?". On that site you can also find a gynecologic oncologist in your area. Click on "Find A Gynecologic Oncologist" and enter your ZIP code.

You can learn more about genetic testing for the BRCA-1 and BRCA-2 gene mutations at www.myriadtests.com/

Women with ovarian cancer and related problems, and their family and friends, can join a free online discussion list hosted by the Association of Online Cancer Resources (ACOR). Go to www.acor.org, click on "mailing lists," choose the Ovarian list and click on it to join. Or go directly to: <http://listserv.acor.org/archives/ovarian.html> and click on "join or leave the list".

CHATTER

Baseball: With the Cardinals' opening day looming, it's not too early to reserve your tickets for Ovaian Cancer Awareness Day at Busch Stadium. This year, as last, SLOCA will be recognized before the first pitch of the Cards vs. Cubs game on Sunday, Aug. 15. Tickets will be \$30 each and will include a cap. Call Grace Katzenberger, 314-849-3970, to reserve your tickets.

Membership: Since beginning its membership drive last year, SLOCA has registered about 200 members. You can join for \$10 a year for an individual or \$25 a year for a household. For information, call Barbara Platzer, membership chairman, at 636-256-0029. You can send a check made payable to SLOCA with name, address, phone and e-mail address to SLOCA at PO Box 270067, St. Louis, MO 63127. Please indicate if you're interested in volunteer opportunities.

Newsletter: This is SLOCA's second newsletter. We are e-mailing an electronic version of it to everyone who has provided us with an e-mail address, and we're sending printed copies to others on our mailing list. We can save money in printing and mailing costs if more people would opt to receive it by e-mail. To do that, e-mail Dede Dierkes at dditto99@yahoo.com with your name, street address, city, state, ZIP, and e-mail address.

Yes! I want to help St. Louis Ovarian Cancer Awareness with its mission. Count me in for the special fun-filled evening

LIVING OUT LOUD

Among the Stars

April 17, 2010 at the James S. McDonnell Planetarium.

Enclosed is my contribution for _____ tickets @ \$100 each.
(You may reserve a table of 8 @ \$800 per table. Please list on the back those whom you wish to be seated at your table.)

I have special food needs. Please contact me at:
(_____) _____

Additional contribution for _____ Star Show drawings @ \$10 each.

I am unable to attend. However, enclosed is a contribution of \$_____ payable to SLOCA.

Please charge my Visa MC AmEx Discover

Credit Card #: _____ Exp. Date: _____

Name (as it appears on card): _____

Signature: _____

Name: _____

Address: _____

City: _____ State: _____ ZIP: _____

Phone: (_____) _____

Email: _____

Please make your contribution payable to:
SLOCA, P.O. Box 270067, St. Louis, MO 63127
Reservation deadline is Friday, April 9, 2010.

2010 BOARD MEMBERS

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Working Women's Survival Show

Nearly 40 SLOCA volunteers passed out literature and talked personally to many of the 20,000 women who visited the Working Women's Survival Show in St. Charles on Feb. 19-21. Here, SLOCA Marketing Director Lisa Sienkiewicz sells a teal crystal bracelet as she urges the buyer to study the symptom cards handed out.

St. Louis Ovarian Cancer Awareness
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