



# TEAL TALKS

DECEMBER 2009

Volume 1, Issue 1

## Dear friends of SLOCA,



Welcome to the first newsletter of St. Louis Ovarian Cancer Awareness. The SLOCA board voted to publish a quarterly newsletter to keep you up to date and involve you in our myriad activities. After this printed newsletter, the next three will be published online as an e-mail blast, so we encourage you to join SLOCA and provide your preferred e-mail address.

SLOCA's mission is to increase ovarian cancer survivorship by promoting awareness of signs and symptoms of ovarian cancer, thereby enabling early diagnosis; promote ovarian cancer research, and support ovarian cancer survivors.

How do we do this? We distribute literature at health fairs, the Working Women's Survival Show, and even Cardinal pep rallies. Ovarian cancer survivors share their personal cancer journeys with third-year medical students at Washington and St. Louis universities, resident doctors at St. John's Mercy Medical Center and nurse-practitioner students at the University of Missouri-St. Louis through SLOCA's program, Survivors Teaching Students: Saving Women's Lives. Every couple of years, we sponsor gynecologic cancer survivors' courses at Washington University.

We also seek opportunities to get the word out through television, radio, newspapers, magazines and online news sites. And SLOCA is always looking for new ways to spread the word about ovarian cancer.

Each year we hold several fundraisers to help cover the costs of SLOCA's mission. In the spring, we hold a dinner auction, and in the fall a fashion show and luncheon. This year, my husband Stuart and I spearheaded the inaugural Trail Ride for Ovarian Cancer, or TROCA. Amy Bell organized an outdoor yoga event, Rise and Shine for a Cure. We are always looking for new fundraising ideas.

With the proceeds from those fundraisers, SLOCA provides a grant each year to the Gynecologic Cancer Foundation (GCF) for research on ovarian cancer. Since SLOCA's inception in 2002, it has donated more than \$165,000 to GCF research efforts. We were pleased this year to be able to support the research of Dr. Premal Thaker at Washington University with a GFC grant.

SLOCA's success would not be possible without its incredible board. They make my job so much easier and I personally want to thank each of them.

I hope you enjoy this newsletter and look forward to the next one. Until then, spread a little teal among your friends and family.

Best wishes,

Karen Higano  
SLOCA President

## INSIDE

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SLOCA's dinner auction is April 17 at the St. Louis Science Center Planetarium. We need donations of goods and services for auction as well as volunteers. Page 2

### Get Involved

Join SLOCA. Want to do more? Volunteer to staff the Working Women Survival Show or a health fair, or help plan a fund-raiser. Call 636-343-7404. Page 3

### Raising Dollars, Awareness

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# DINNER AUCTION

Save the date of Saturday, April 17 for SLOCA's annual dinner auction.

The St. Louis Science Center Planetarium will be the site of this year's event, "LIVING OUT LOUD AMONG THE STARS."

We changed venues this year to add excitement to our premiere fundraising event of the year. The dinner auction will begin at 6:30 p.m.

We hope you will join us for a fun-filled evening with silent and live auctions, dinner under the stars and much more.

Look for more information on our Web site, [www.sloca.org](http://www.sloca.org), in coming months and expect to receive an invitation in March.

Last year's dinner auction raised a net total of \$25,671 to be used toward research grants and SLOCA's awareness outreach programs.

We need your help to make the evening a success.

We need items and services donated for auction and companies that would be willing to sponsor the dinner auction.



Michele Beyer of Portland, Oregon, made this quilt and donated it for the 2010 auction. Michele is the daughter-in-law of a friend of SLOCA Membership Chairman Barbara Platzer.

Last year, we auctioned off luxury trips, a week at a Florida condo, sports memorabilia, the first pitch at a Cards-Cub game, jewelry, artwork, spa services, gift baskets, a bicycle, golf lessons and pet food coupons.

We also need volunteers to help plan and prepare for the auction and to work it that night.

If you can help in any of those ways, please contact Karen Higano at [hoeflerlin4@aol.com](mailto:hoeflerlin4@aol.com).

**What:** Living Out Loud among the Stars

**When:** Saturday, April 17

**Where:** St. Louis Science Center Planetarium

**Ticket price:** \$100

**Fundraising goal:** \$30,000

**Donate goods/services:**

Karen Higano  
314-680-9617  
[hoeflerlin4@aol.com](mailto:hoeflerlin4@aol.com)

**Volunteer:**

Lisa Sienkiewicz,  
314-882-1388  
[lisasienkiewicz@hotmail.com](mailto:lisasienkiewicz@hotmail.com)

# GET INVOLVED IN SLOCA

## Working Women's Survival Show



**S**t. Louis Ovarian Cancer Awareness is more than our organization's name. Awareness is our mission. We aim to increase ovarian cancer survivorship by promoting awareness of early warning signs and standards of care, enabling early diagnosis and promoting ovarian cancer research and survivor support.

The signs and symptoms of ovarian cancer are subtle, and all women need to know them. The major symptoms are: Bloating, pelvic or abdominal pain, urinary urgency or frequency, difficulty eating or feeling full quickly, constipation or diarrhea.

Others can include nausea, indigestion or gas; constipation or diarrhea; unusual fatigue; unexplained weight gain or loss; shortness of breath and rectal pain (sometimes during intercourse).

The SLOCA board and its friends, families and volunteers spend many hours reaching out to women throughout the Greater St. Louis area, and on fundraisers to pay for awareness materials. One excellent place to reach out to women is the annual Working Women's Survival Show, which will be held this year at the St. Charles Convention Center on February 19, 20 and 21.

Events like the Working Women's Survival Show cost SLOCA not just the price of the booth and materials, but many hours of volunteer staffing. It's an excellent opportunity for everyone who believes in our mission to reach out to many women in the greater St. Louis area.

If you would like to volunteer at the Working Women's Survival Show, or for other of SLOCA's activities, call me at 636-343-7404. We will supply you with an entry badge for the Working Women's Survival Show. So call your friends, volunteer for a couple of hours and stay longer to enjoy the Working Women's Survival Show!

Lisa Sienkiewicz  
Marketing Chairman

## JOIN US

**S**t. Louis Ovarian Cancer Awareness began formally enrolling members in 2008, and it's now asking members to renew and friends of SLOCA to join for the first time.

As of November, SLOCA had about 130 members, and we would like to invite other ovarian cancer patients, survivors, family members, friends and medical professionals to join.

We also extend an invitation to anyone who is interested to attend a SLOCA board meeting. The meetings are held on the third Thursday of each month (except December) at the Pratt Cancer Center at St. John's Mercy Medical Center. Meetings begin at 6:45 p.m.

We hope you will fill out the membership envelope and include your e-mail address in the designated space. We will not share that information with anyone. We hope you'll opt to receive future newsletters by e-mail to help us save on printed and postage costs.

We hope you will fill out the membership envelope enclosed with this newsletter and we appreciate your support.

Barbara Platzer  
Membership Chairman  
636-256-0029

# SLOCA KICKS OFF NEW EVENTS



## YOGA

**R**ise and Shine for a Cure -- 108 Sun Salutations for Ovarian Cancer Awareness took place on a glorious Saturday, September 26, at The Artists' Guild pavilion at Oak Knoll Park. About 60 people took part, and the event raised a net total of \$1,806.

The event was the brain-child of Amy Bell and was created for her community project in Landmark Education's Self Expression and Leadership Program (SELP). Landmark Education is a global educational enterprise committed to the fundamental principal that people have the possibility of success, fulfillment and greatness. SELP is one of its core programs.

Amy began advocating for awareness of gynecologic cancers after doctors diagnosed her Aunt Cathy with primary peritoneal cancer in 2005. Amy and Cathy shared a love of yoga, and Cathy occasionally visited St. Louis for yoga workshops.

As she considered what sort of community project she wanted to take on, Amy spoke to Grace Katzenberger, a founder and immediate past president of St. Louis Ovarian Cancer Awareness. She connected Amy with Ina Sachar, who was a board member and a yoga teacher. Ina immediately got on board, and Amy secured two chairwomen for the project -- Diana Lucas, a wellness specialist, and Michelle Abounader, a local yoga teacher.

The biggest challenge was time; the group had less than two months to pull the project together in time for Ovarian Cancer Awareness Month in September. They met every Thursday at Kaldi's in Clayton's DeMun area to brainstorm and delegate.

"It was key for all of us to keep remembering that the almost certain probable future without action is that more women would die from this disease," said Amy. Rise & Shine created the possibility to raise money and educate people, help fund a cure and save lives, she said.

Many other people donated their time and money to make the event a success.

Over a period of three hours, 12 area yoga instructors each led nine Sun Salutation yoga movements. Accompanying them on African flute, drums and Tibetan bowls were Bradford Smith and Friends. Diana Lucas chanted.

Kaldi's donated coffee and Companion Bakery provided bagels for the event.

"One lesson I learned that is if you ask for help, share the possibility of the project and are specific about your needs people willingly help you in ways you couldn't imagine," Amy said.

Rise & Shine will live on. Plans for next year's event are in the works. Mark your calendars for August 29 at the World's Fair Pavilion in Forest Park.



## BICYCLING

**I**magine starting a new life with a husband, a new home and a baby on the way. The excitement of so many changes and dreams come true. Life is capable of producing sharp twists and turns, but getting the news in the midst of this joy that you have ovarian cancer is more like hitting a speed bump at top speed.

That's what happened to Karen Higano, wife, mother and president of St. Louis Ovarian Cancer Awareness.

More than two-thirds of women who are diagnosed with ovarian cancer are in the later stages of cancer, when they have a 46 percent chance overall of surviving five years. Fortunately for Karen, a Caesarean section for her son's delivery led to early diagnosis of her cancer. Her prognosis is very good.

There is currently NO method of early detection for ovarian cancer and too many women mistakenly believe that a Pap test will detect any gynecologic abnormality. This is not the case for ovarian cancer. Only recently have early physical signs and symptoms been published so that women may use them as a guide when talking to their doctors.

So how does a girl celebrate victory over ovarian cancer? Does she indulge in a two-week cruise on a ship in warm waters? How about a stay in a Tuscan villa or an extended weekend at a Southern California spa?

Not Karen. An avid bicyclist, she set as her post-treatment goal completion of a century bike ride. Yes, that's 100 miles. With her husband Stuart she did just that, riding Lance Armstrong's "Ride for the Roses" in Austin, Texas, in October 2005.

This year the Higanos married their love of bicycling with their passion for spreading the word about ovarian cancer. They launched a new event to raise money for SLOCA, calling it Trail Ride for Ovarian Cancer, or TROCA. With a friend, Robert Koop, they spent three days, September 10-12, riding the 230 miles of the Katy Trail from Clinton, Mo., east to St. Charles. Another ovarian cancer survivor, Jan Paul, joined them on their last day's ride, from Hermann to St. Charles.

The result of Karen's efforts? TROCA took in \$12,345 in donations and pledges to be put toward research grants and SLOCA's work of educating women to the signs and symptoms of ovarian cancer.

Planning for TROCA 2K10 is under way. If you want to participate or to volunteer in a support role, e-mail Karen at [hoeferlin4@aol.com](mailto:hoeferlin4@aol.com). If you want to learn the signs and symptoms of ovarian cancer, go to [www.sloca.org](http://www.sloca.org) and click on Ovarian Cancer, then Symptoms.

# ASK THE DOCTOR



Dr. Mutch

The past five years have been exciting for ovarian cancer patients in that there have been several significant advances in the treatment of this disease.

First, a study known as GOG 172 was completed. Once again, it verified that patients who underwent a maximal cyto reductive effort and were optimally cyto reduced at initial surgery and underwent intraperitoneal chemotherapy enjoyed a significant survival advantage over those who received traditional intravenous chemotherapy. The median survival of women who could tolerate all six cycles of the intraperitoneal treatment was more than 10 years. Those who could complete two cycles also enjoyed a survival benefit over those who underwent standard therapy.

The biggest problem with this therapy is its toxicity. Only 40 percent of patients could tolerate treatments and were able to receive all six cycles of treatment. Complications of treatment can include permanent kidney damage. For that reason, it's important to monitor patients undergoing this treatment for evidence of dehydration or decreased ability to take liquids by mouth.

GOG 182 was recently completed. This is a trial that randomized patients to five different combination platinum based treatments and included paclitaxel as a control arm. Other drugs used were gemcytibine, liposomal doxorubicin and topotecan. Interestingly, all arms were equivalent. Taxol remains the standard of care but the results show that other agents are just as effective. If unacceptable toxicity to paclitaxel occurs, other drugs can be substituted, making treatment options more flexible.

Finally, the Bevasizumab (avastin) is now available for recurrent disease. This drug can be added to almost any regimen to improve response. Unfortunately, the drug is very expensive and has some complications. The most notable bad side effects are protein in the urine, hypertension and bowel perforation. It is not always appropriate to use avastin and it is important to follow your physician's recommendation in this setting.

Several new trials are available in the St Louis area. The first is a maintenance trial in which additional single agent chemotherapy is administered for up to a year after completion of standard chemotherapy. The goal is to determine if low dose treatments will prevent the cancer from returning.

Another trial uses Alimta and Beviszumab in patients with recurrent disease. Several other trials using biologic agents are available at Washington University.

As a result of such trials, ovarian cancer patients have experienced a continued improved survival in the past five years. We hope that newer agents and better support will continue this trend over the next five years.

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

## Donate to Honor Someone

SLOCA relies on donations for about 18 percent of its budget. Each year, supporters generously send SLOCA gifts ranging from \$5 to several hundred in memory of a loved one who has passed away or in honor of a survivor, doctor, nurse or caregiver.

Beginning Jan. 1, we will begin listing those who are honored and memorialized and their donors in upcoming newsletters.

You may make a donation by sending a check payable to SLOCA at P.O. Box 270067, St. Louis, MO 63127. Specify the individual being honored or memorialized, and give your name and address and that of the person to whom you would like an acknowledgment sent. Or call 314-995-6220 and leave a message.

Donation envelopes for SLOCA also will be available at all of the health fairs and events in which SLOCA participates. We thank you for your support.

# BRIEFS

## Buy a Hope Light Brick

Rudy and Bev Bess founded The Hope Light Foundation after losing a relative and a friend to cancer within a span of 15 minutes on the Fourth of July, 2005.

HLF is a non-profit charity dedicated to educating people about cancer prevention, signs and symptoms, screening tests, self-exams and the importance of leading healthy lifestyles. Its goals are to promote early cancer detection and increase survivorship.

Plans are under way to build a Hope Light in Metropolis, Ill., on the bank of the Ohio River. Its 50-foot-tall tower will be topped by a lantern room with a white flashing light; a teal band will represent ovarian cancer. A cancer information kiosk will offer cancer information.

You may buy a brick for the terrace and walkways and personalize it in memory or honor of individuals or organizations by going to [www.hopelightproject.com](http://www.hopelightproject.com).

SLOCA has provided Hope Light with encouragement and financial support.

## Use eScrip Card at Schnucks

It doesn't cost a penny to support SLOCA through Schnucks'eScrip program. Since SLOCA joined the program in September, 25 of its members and friends have signed up for eScrip.

Just pick up an eScrip card at a Schnucks courtesy counter. Call the 1-800 number on the card to register that card in support of St. Louis Ovarian Cancer Awareness.

Each time you shop at Schnucks, present the card to the cashier. eScrip will rebate to SLOCA 2 to 3 percent of the purchases.

It's that easy. Really. Pick up a card today for yourself, your spouse, your parents, children and neighbors. You get the idea.

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## 2009 BOARD MEMBERS

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Karen Higano – President  
Charles Hapke – Vice President & Attorney  
Jan Paul – Treasurer  
Carol Reinheimer – Recording Secretary  
Nancy Marron – Corresponding Secretary  
Grace Katzenberger – Past President – Emeritus  
Lisa Sienkiewicz – Director of Marketing  
Barbara Platzer – Membership  
Kitty Lasinski – Webmaster  
Joanne Henderson – Historian  
Merle Miller  
Jackie Morris  
Dale Wood Dallas  
Ina Sachar  
Diana Padratzik  
Selma Balk  
JoAnn Carter – Emeritus  
Diane Harrison – Emeritus  
Judy Parham – Emeritus  
Nancy Larson-Vomund – Emeritus  
Bob Hardcastle – Honorary  
Dr. David G. Mutch – Medical Advisor



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## LADIES WHO LUNCH

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From left to right: SLOCA board members Barbara Platzer, Grace Katzenberger, Jan Paul and President Karen Higano, and First Lady Georganne Nixon met for a luncheon in September in Jefferson City on the state of ovarian cancer.

St. Louis Ovarian Cancer Awareness  
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