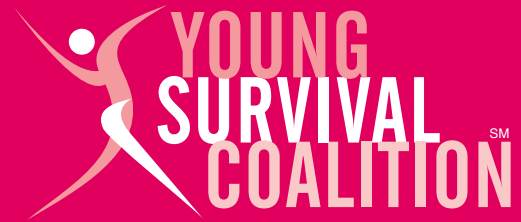


YOUNG PERSPECTIVE

YSC Unveils New Website



Spring 2002

After months of planning and fundraising, the Young Survival Coalition kicked off 2002 by unveiling its newly redesigned website, www.youngsurvival.org.

"The website is the face of the YSC," says Executive Director Michele Przypyszny. According to Przypyszny, the site will help raise public awareness of breast cancer in young women and draw national attention to the YSC.

The new site is the only comprehensive online resource for young women with breast cancer in the world. Personal essays from young survivors and an extensive discussion board offer information and support to other young women and their loved ones seeking advice, coping mechanisms, and encouragement, as well as a forum for sharing fears and frustrations.

"The site is very comforting for those who are newly diagnosed," says New Yorker Christine Sansone, who was diagnosed two years ago at age 25. She also praised the wide array of easy-to-navigate resources available for those living with the disease.

The site also serves as a focal point to gather information on young women and breast cancer

that can be disseminated to medical professionals and important research organizations.

Toward that end, YSC President Cindy Rubin urges all members to register on the new site (see Letter from the President). The membership registration form includes questions about demographics, diagnosis, and treatment, and the YSC Membership Profile is automatically updated with each new registration to reflect the latest statistics about YSC members. The YSC needs every one of its members to register on the new site in order to demonstrate to the medical and research communities that the young survivor population is sizable enough to warrant their attention and study.

In addition to re-registering on the new site, YSC members are encouraged to share their personal experiences in the form of Survivor Stories. Submissions should be sent to stories@youngsurvival.org.

The YSC would like to thank The Big Bam! Foundation and an anonymous donor whose generous support made the newly designed website possible.

INSIDE

Letter from
the President
LBBC/YSC Conference
Survivor Spotlight
YSC in Your Community
Mt. Sinai Study
Reach to Recovery
Program
San Antonio Breast
Cancer Symposium
Fighting for
Our Future

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Letter from the President

I must start this letter with a plea: If you have not yet registered on the new YSC website (www.youngsurvival.org), please do so—and ask everyone you know to register as well. We now have three separate registration forms: survivor, friends and family, and medical community. From survivors, we are collecting information (which is completely confidential) that will help us influence researchers to conduct studies of young women and breast cancer. Our registration form includes information about who we are, what kind of cancer we had and what treatment we received. Every time a new member registers, the YSC membership profile is automatically updated and can be viewed on the site. Most of you are familiar with my refrain: there is power in our numbers. So please do your part to increase studies about young women and breast cancer: register and be counted.


For the past few months, several committed YSC volunteers have been focusing on growing our grassroots organization of 1,400+ members into the major national breast cancer organization we are becoming. In addition to our groups in Atlanta, Florida, and Indiana, we now have YSC groups forming in Tennessee, Illinois, Massachusetts, and California, among other places. We have established a process, a three-tiered structure (YSC local contact, YSC Networking Group, and YSC Affiliate), and policies for our growth in local communities around the country. Handbooks and information on all three levels of involvement have been developed for those interested in participating in their communities.

Our new website is another major project that we completed in the past few months. We believe that it is the most comprehensive

resource on young women and breast cancer in the world. It is also one of the most dynamic sites on the web, with constantly changing information on current research, events and YSC members and activities around the country.

The second annual Conference on Young Women Affected by Breast Cancer and the second annual YSC Leadership Retreat were both held this past February. The day-long conference, hosted with Living Beyond Breast Cancer, drew close to 500 young women; 80 YSC leaders from around the country attended the retreat the following day. We used the retreat to set our national goals and design strategies to achieve them.

We have completed collecting data for the first YSC-sponsored research study on young women and breast cancer, and I thank each of the 529 YSC members who participated in the survey, on which we collaborated with the Mt. Sinai School of Medicine in New York City. The 100-question survey was designed to reveal the gaps in research on young women and breast cancer so that we can concentrate our future efforts on those areas. Stay tuned for the results.

The past few months have been a time of enormous growth for the YSC, as evidenced in these pages. We are reaching out to more women than ever and achieving our goal of impacting research on young women and breast cancer. Despite our rapid progress, there is always more that can be done, and the ambition, commitment and dedication of the YSC volunteers around the country will continue to give young women a bigger and clearer voice in the breast cancer community. 

—Cynthia Rubin, YSC President

“The 2nd Annual Conference for Young Women Affected by Breast Cancer” Brings Together Close to 500 Young Breast Cancer Survivors

The 2nd Annual Conference for Young Women Affected by Breast Cancer: “Living Well Today for the Promise of Tomorrow” was held in Philadelphia on February 23rd. The conference was produced by the Young Survival Coalition and Living Beyond Breast Cancer (www.lbcc.org), and was attended by close to 500 young women, supporters, and medical professionals who traveled from 29 states, the District of Columbia and Canada -- many of whom were YSC members. The conference was underwritten by corporate sponsors Bristol-Myers Squibb, breastcancer.org, Genentech, GlaxoSmithKline Oncology, and Roche Pharmaceuticals.

“We were very excited to co-present this Conference, which brought young survivors together to learn even more about the issues that face us and to network with other young women,” commented Cynthia Rubin, President of the Young Survival Coalition. “It was very gratifying to see that the YSC and LBCC are reaching more and more young women, and we look forward to presenting more programs in the future that will focus on issues important to this under-served population.”

The day-long event began with a panel of leading breast cancer specialists addressing medical issues of importance to young women with breast cancer. The panel was moderated by Marisa C. Weiss, MD, Founder and President of breastcancer.org and LBCC. Dr. Weiss introduced panel

members Kevin Fox, MD, Associate Professor of Medicine and Director of the Rena Rowan Breast Center at the University of Pennsylvania Cancer Center; Jeanne Petrek, MD, Director, Surgical Program at Memorial Sloan-Kettering Cancer Center; and Bert M. Petersen, Jr., MD, Director of Family Risk Programs at Beth Israel Cancer Center.

The panel provided an overview of the latest oncology treatments, future research goals, reconstruction options, and genetic factors. At the conclusion of the presentations, Dr. Weiss fielded questions from the audience addressing such topics as nutrition, complementary medicine, Tamoxifen efficacy, and lymphedema.

Following lunch, participants selected two 90-minute special-interest workshops. Topics included Fertility and Pregnancy After Breast Cancer; Managing Premature Menopausal Symptoms; Clinical Trials: Changing Treatment Options; and Tamoxifen: Risk vs. Reward.

The conference concluded with inspiring remarks by Dr. Ernie Bodai of Kaiser Permanente’s Sacramento Medical Center. Dr. Bodai successfully lobbied Congress to establish the breast cancer stamp, which has raised more than \$20 million for breast cancer research.

Tapes of the conference are available for purchase by calling LBCC at (610) 645-4567. 

The Young Survival Coalition would like to thank Hoffman La-Roche for making the printing of this newsletter possible.


I was 22 years old, and I had just come back from a fun summer doing medical research in Holland, when I told my parents that I felt a lump. They hoped it was just a cyst, but they scheduled an appointment for me to meet with a surgeon right away. My parents are physicians, and my surgeon was a colleague and friend.

didn't. I got through second year, studied for exams, went on a two-week trip to Spain with a friend, and then started my third year of school, very excited to be working "with real patients" instead of just reading about it. In October of that year, I developed a dry cough, which I thought was just something I had caught from

returned to medical school, and my former classmates have graduated and are almost finished with their intern years of training. My cancer is under control, and I feel great 95% of the time. A few weeks ago I started on a new medication, Femara, which in addition to another drug, Zoladex, will almost completely stop all estrogen production in my body.

We have already seen good results from this hormonal treatment alone, without chemotherapy. I am very

hopeful that this non-cytotoxic treatment will continue to work for me.

I just turned 26 in December. Now that I am off of chemo, I have been able to do more physically, which has allowed me to be more active socially. My plans for my education and career are still unclear. I love children; I wanted to become a pediatrician. I also want to have a family of my own, but that seems far away right now. I am lucky to have great parents, an older sister, a younger brother, and some good friends to help me along. I am also very pleased that I found the help and support of the YSC. 

Since Nalini wrote this story in 2001, she has gone back to medical school full time and just finished her mid-year exams.

SURVIVOR SPOTLIGHT: I Wanted to Treat Ill Patients, Not Become One: NALINI YADLA The Story of a Medical Student/Breast Cancer Survivor

I actually got the news on the first day of my second year of medical school. I had to read it, because my father could not find the strength to say it. I had ductal carcinoma in situ. I couldn't believe it. After consulting with local academic experts, I had a mastectomy just 3 days later, and was back in school a week after that. The lecture on my first day back was "Tumor Immunology."

I was told that my lymph nodes were negative, the surgical margins were clear, and, because DCIS is non-invasive, I was all clear. It happened so fast that I barely had time to think about it. All I thought about was catching up on all the school-work I had missed. I never had a fear of death, or even of actually being sick, and my doctor assured me not to worry. So I

someone, but it never went away. Every time I tried to talk, I had to cough first. During winter break, I got a chest X-ray done to figure out what was happening. The X-ray technician said, "You're a med student right? You want to take a look at this?", thinking it would be fun to look together and find a little glob from a pneumonia or something. When the X-ray came out of the machine, I thought there must have been a mistake. Why were there all these white spots all over my lungs?

My DCIS must not have been DCIS at all — the breast cancer had silently spread to my lungs and brain. I received chemotherapy from January of 1999 until March of 2001, and had radiation treatments to my brain. I have not

YSC and Mt. Sinai School of Medicine Team Up in Study of Young Survivors

If you think there isn't enough breast cancer research on young women, you are right — but today, members of the YSC are changing that! YSC and Mt. Sinai School of Medicine in New York City have partnered on a research study of young women with breast cancer. The survey covers demographics, medical history, diagnosis, treatment, and quality of life, as well as thoughts and feelings on diagnosis, physicians, and future outcomes. The survey was designed by the Mt. Sinai School of Medicine's Department of Human Genetics in consultation with the YSC.

About 530 (46% of the YSC's survivor membership) young survivors completed the survey, and the data collected is now being analyzed. Mt. Sinai and the YSC are hoping that the results will enable a clearer picture of young women and breast cancer to be developed and, as importantly, provide the medical and research communities with statistics showing the merit of more research on this underserved population. Stay tuned for results from this exciting and ground-breaking project!

YSC to Present Young Women's Issues at 2002 World Breast Cancer Conference

YSC has been invited to present multiple sessions at the upcoming World Breast Cancer Conference on June 4-8. Topics will include "Overview of the Unique Challenges of Early Onset Breast Cancer and the Need for Global Collaboration" as well as an interactive workshop on: "Making a Difference: How to Become an Effective Breast Cancer Advocate". In addition to these sessions, there will also be a screening of "Fighting for Our Future: Young Women United Against Breast Cancer", Emmy-nominated film maker Beth Murphy's documentary about the YSC (see page 7 for details)

The goal of the World Conference on Breast Cancer is to build an international action network to fight this deadly disease. In 2002, an expected 800 to 1,200 delegates from more than 80 countries will gather in Victoria, Canada to share ideas and plan action for the eradication of breast cancer around the world. The YSC is honored to be among the many scientists, doctors and advocates who will converge from around the globe for this prestigious event.

For more information on the Conference, please visit <http://www.worldbreastcancerconf.ca> > www.worldbreastcancerconf.ca. If you have questions about the YSC's participation or are planning to attend, please be sure to let us know by contacting <mailto:programs@youngsurvival.org> > programs@youngsurvival.org

From the YSC Bulletin Board – I am 29 years old and was diagnosed with invasive ductal carcinoma, stage IIIA. . . . I am single and recently moved to start a new job, so my support system is fragile. . . . I am glad to find this site!

YSC Joins Forces with the American Cancer Society in New York City: Revised Reach to Recovery Program and New Brochure Will Address Young Women's Issues

In October 2001, the Young Survival Coalition and the Manhattan/Bronx office of the American Cancer Society (ACS) began working together to adapt ACS's Reach to Recovery program to better address the unique needs of young women diagnosed with breast cancer.

Reach to Recovery is a peer support program that connects newly diagnosed women with trained volunteers who are themselves breast cancer survivors. Reach to Recovery is one of the oldest programs of its kind and has been connecting women since 1969.

Together in partnership, ACS and the YSC have added to the existing Reach to Recovery training program so it incorporates young women's issues as part of its discussion of patient diversity. Additionally, this year's annual re-certification meeting will be devoted entirely to the unique needs and concerns of young women with breast cancer. Re-certification meetings are annual events where new and important information is given to all active Reach to Recovery volunteers.

This pilot program serves all of Manhattan and the Bronx. The two organizations are actively working together to recruit and train more young women to serve as peer counselors through the Reach to Recovery program.

In addition to Reach to Recovery, ACS and the YSC are collaborating on a brochure specific to young women newly diagnosed with breast cancer. One factor that contributes to the sense of isolation as younger women with breast cancer is the lack of age-appropriate printed material. Young women

have told both the YSC and ACS that much of the printed material they receive about dealing with breast cancer is geared toward women the age of their mothers. Since so many young women turn to ACS and the YSC when they are diagnosed, it is our hope that this new brochure will help them understand that they are not alone as well as provide additional resources.

The YSC is delighted to be working with the Manhattan/Bronx office of the American Cancer Society and is very appreciative of their support as together more young women with breast cancer will be reached. 

Want young women to be addressed in your local Reach to Recovery programs?

The YSC hopes that the partnership with the Manhattan/Bronx Reach to Recovery program is only the beginning of a nationwide collaboration between the two organizations. If you are interested in working with your local ACS to better serve young women in your community, call your local ACS representative at 1-800-ACS-2345, and tell them about the work ACS and YSC are doing together in New York City. For more information, contact Randi Rosenberg, YSC's Educational Programming & Medical Outreach Officer, at 212-916-7667 or programs@youngsurvival.org or Elizabeth Tarr, CSW, Director of Patient and Family Services for the American Cancer Society at (212) 237-3828 or elizabeth.tarr@cancer.org.

Fighting for Our Future: Young Women United Against Breast Cancer

The Young Survival Coalition, in conjunction with Passport Productions, Inc. and the talented, Emmy-nominated filmmaker Beth Murphy, is producing "Fighting for Our Future," a one-hour documentary on the YSC and young women and breast cancer.

The documentary chronicles the experiences of the YSC's founders Joy Simha, Roberta Levy-Schwartz and Lanita Hausman, along with members Tracy Pleva Hill, Lisa Muccillo Rodriguez, Aquatia Owens, Cindy Rubin, Randi Rosenberg, Juanita Lyle and Kelly Douglas. The film follows these young survivors as they go through treatment, talk about founding the YSC, participate in the National Breast Cancer Coalition annual educational conference and Lobby Day on Capitol Hill, kick-box, kayak, play with their children, and tell what the experience of breast cancer as a young woman means to them every day.

The documentary, which we hope will air this fall, will be joined by a companion book — featuring survivor stories, medical information, statistics on young women, and information on how to cope — and an educational video to be

sent to doctors to help young patients diagnosed with breast cancer. The educational video highlights issues of specific concern to young women and breast cancer including fertility, pregnancy, premature menopause, hormonal therapies, research and clinical trials, insurance, and sexuality and intimacy.

"We hope the documentary, companion book, and educational video will bring hope to thousands of young women living with breast cancer and raise awareness among young, healthy women and the medical community that young women can and do get breast cancer. The message to healthy women is: be aware, do breast self-exams, and get a yearly clinical exam by your doctor. As importantly, the medical community needs to realize that 'you are too young' is not a diagnosis," says Cindy Rubin, YSC President.

"Fighting for Our Future" was made possible through the generous support of ROCHE Pharmaceuticals and an anonymous donor. 

For more information on the documentary, contact info@youngsurvival.org or call the YSC offices at 212-916-7667.

From the YSC Bulletin Board – Hi everyone. I'm just reaching my 20-year survivor date. I'm so excited to see this website. I had breast cancer when I was 26 and had a mastectomy. I had all of these concerns and no one to talk to about it. It's great you're here.

A Patient Advocate's View of The San Antonio Breast Cancer Symposium by Lori Atkinson, YSC Indiana

The Alamo Breast Cancer Coalition (ABCC) has developed a program for advocates, which is offered in conjunction with the San Antonio Breast Cancer Symposium. Through a scholarship given by the ABCC, I was lucky enough to have the opportunity to attend along with 40 other advocates from Canada, Sweden, Australia and the U.S. This is an international conference in its twenty-fourth year, attended by over 4,000 medical professionals, researchers, and advocates.

Besides meeting doctors and researchers specializing in breast cancer, each advocate is given a mentor who can help them through the maze of breast cancer research and help determine which sessions to attend. As well, each advocate must write a paper on a "Hot Topic" selected from a lecture or a poster session – and there were 580 studies presented to choose from. Talk about grueling! The Hot Topic papers are then compiled together and utilized as an encyclopedic overview of the conference from a non-scientific perspective.

We were also able to participate in the case study luncheons during which breast cancer case studies are brought before a panel of doctors for discussion. This was of utmost relevance to the YSC, as most of the cases brought to the panel were regarding women in their 20's and 30's. When I questioned one of the doctors as to why all the cases were about young women, his comment was "that's because those are [usually] the hard ones." It was evident there are many different factors to consider in planning a treatment for a young breast cancer patient.


Several of the pharmaceutical companies participated in the advocacy program by offering breakfast and a tea that was

just for the advocates. It was a great time to meet others and to find out about other organizations and their programs. Fran Visco, President of the National Breast Cancer Coalition, opened the first general session and spoke on the role of breast cancer advocates in setting and advancing research agendas. This was the first time an advocate had been asked to speak at the conference.

The conclusion of most of the studies presented favored aromatase inhibitors over Tamoxifen -- which are generally indicated for use in post-menopausal women. Other studies showing promising results were on Herceptin, screening techniques, ovarian suppression, genetics, and bisphosphonates. All of the abstracts concerning these studies (and more) can be found online at www.sabcs.org.

The treatment for breast cancer promises to become more individualized for each patient due to all of the research being done. Treatment may no longer contain "guesswork" by the doctor. Instead, doctors will be able to use the information from the tumor sample to detect what the underlying diagnosis is and specialize the treatment for the patient.

As a breast cancer survivor and an advocate, the information was encouraging, but also discouraging as we are not any closer in finding breast cancer's cause or a possible cure.

Attending this conference has given me invaluable knowledge which has fueled my passion to help others through their battles. With this type of information, I know I can help educate patients and encourage them to find answers and the best treatments available. 

In Your Community

To find out if there are members meeting locally near you, call the YSC office at (212) 916-7667 or email one of the following YSC groups:

Atlanta April Shuford
(yscatlanta@youngsurvival.org)

California Kim Golding
(ysccalifornia@youngsurvival.org)

Florida Karen Sattaur
(yscflorida@youngsurvival.org)

Indiana Lori Atkinson
(yscindiana@youngsurvival.org)

Massachusetts Margo Wald
(margo_wald@yahoo.com)

Tennessee Amy Thomas
(jathoma@bellsouth.net)

Washington, DC Leslie Frank
(leslienva@msn.com)

In February, the **Atlanta** YSC affiliate held its first fundraiser, including a silent auction and karaoke contest. Funds raised will be used to promote local educational and awareness programs for healthy young women.

Members in **California** held a young survivors' tea in the San Francisco Bay Area in February. Featured at the tea was a guest lecturer from a local hospital who spoke about warning signs and treatments for lymphedema.

Florida YSC members hosted a table at the Komen Race for the Cure, in January and promoted their affiliate to local survivors. Monthly meetings are now accessible statewide through conference calls.

Indiana YSC members have developed an outreach program including gift baskets for new members undergoing treatment. The YSC team will run in their local Komen Race for the Cure, in April, and they will host a golf tournament in May.

YSC members in **Massachusetts** are now meeting once a month to talk about how they can promote breast cancer advocacy and awareness in their community.

Tennessee YSC members visited with the Atlanta affiliate in January and are working to establish a local YSC group in the middle Tennessee area.

Many of our members meet monthly to discuss ways they can bring the YSC's mission to their community, such as becoming involved with their state breast cancer coalition; talking to the press; bringing brochures to their doctors' offices; working with local breast health organizations; and staffing a YSC table at a local breast health fair or other event.

Congratulations to YSC local groups in **Atlanta, Indiana** and **Florida** for receiving educational grants from their local Susan G. Komen Breast Cancer Affiliates.

Shop for the YSC!

**Loehmann's Manhattan,
7th Avenue at 16th Street
Tuesday, April 16, 2002
5:30-9:30PM**

Loehmann's Manhattan store will be hosting a VIP Shopping Night on Tuesday, April 16, 2002, with a percentage of the proceeds to benefit the YSC. Thousands of designer items will be available at Loehmann's great discount prices. Special invitations will offer an additional 15% discount to YSC shoppers. **Thank you, Loehmann's!!**

YSC MISSION STATEMENT

The Young Survival Coalition is the only international network of breast cancer survivors and supporters dedicated to the critical concerns and issues unique to young women and breast cancer. Through action, advocacy and awareness, the YSC seeks to educate and influence the medical, research, breast cancer and legislative communities to address breast cancer in women 40 and under, and to serve as a point of contact for young women living with breast cancer.

The YSC would like to thank the following contributors to the Spring 2002 "Young Perspective". It is through the talents of our volunteers nationwide, that the "Young Perspective" is brought to you quarterly.

Lisa Ammerman, New York, NY
Lori Atkinson, Middletown, IN
Becky Beane, Benton, ME
Kari Bibbi, Nashville, TN
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Roberta Levy Schwartz, Houston, TX
Randi Rosenberg, Jersey City, NJ
Cynthia Rubin, New York, NY
Jeannine Salamone, Alexandria, VA

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From the YSC Bulletin Board – I was just wondering if anyone else loses their train of thought, or is it just overload for me? I hope this memory loss thing is temporary. I was diagnosed in July 2001, after my 37th birthday. I have stage IV.

Thank You for Your Support! The YSC gratefully acknowledges the generous contributions of:

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