

New Attitudes

A newsletter dedicated to understanding and preventing breast cancer.

President's Message



Greetings! This year is going by so fast! I can't believe we are at the end of July and ready for August to begin!

We have been so busy with Between Women projects. We began this year with a collaborative effort of cancer informative workshops to the

"faith community." Thanks to the help of the American Cancer Society, Pioneers Health Centers, Imperial County Health-Public Health Services and A Place of Angels, the workshops have been very productive, in Spanish (with the Comadre Program) as well as English and including the Teen Program. We plan to reach about nine additional churches in the Imperial Valley before the end of the year. Equipping these people with cancer awareness, as well as literature to take home with them to share with others, has been a wonderful experience. We were given interesting questions to ponder and inquire about ourselves. We are ALL still learning and will continue learning about cancer until we have a CURE!

Elizabeth Arispe and I attended a Leadership Conference in early March. We received continued training for our support groups as well as "one-on-one peer support" for newly diagnosed women. These workshops are valuable to the success of the programs we already have in place as well as training the people involved in these programs. In addition to these workshops, support meetings and supporting newly diagnosed women, we have had our monthly Board meetings for the upcoming luncheon on September 29, 2001.

Elizabeth Arispe and I attended our first National Breast Cancer Coalition Conference held in Washington, D. C., May 5th through the 9th. The

conference title was "Going the Distance to Make Breast Cancer History." We were very grateful to the Brawley and Calipatria P.E.O. organizations for their partial financial support in this conference. We had the opportunity to learn of the urgency to be advocates, with a clear and resounding voice, here in our Imperial Valley on breast cancer bills that need our support as well as the necessary action! If you would like to hear from us and want to receive updated information about these bills, please e-mail me at betweenwomen@yahoo.com. The more people responding to legislative mail, the better!

Our trip to Washington, D.C., was indeed very costly. If you would like to help offset the expenses incurred on this trip, you may send a tax-deductible check to Between Women, 207 West Legion Road, Brawley, CA 92227. We would also appreciate your prayers for our continued success with our legislators when future breast cancer bills need immediate attention.

I am devoting this publication mostly to advocacy. Between Women feels this is another tool to be used for eradicating cancer in our lifetime. Let's make breast cancer HISTORY indeed!

God Bless!

— Linda Cady, Founder and President

Lymphedema - A Condition, Not a Disease

Lymphedema is poorly understood and difficulties arise when attempting insurance coverage of treatment. The 105th Congress signed the Women's Health & Cancer Rights Act (WHCRA) of 1998, which mandates that all insurance companies provide coverage for "prostheses and physical complications of mastectomy, including lymphedemas." Although the law needs to be

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more specific, it is an important beginning. Recently, California passed a state law that runs parallel to the federal law and is more comprehensive. Hopefully other states will follow suit.

Insurance companies must be convinced that this is a medical condition and not a rehabilitation problem. Specially trained CPT therapists should not be excluded as healthcare providers because they are massage therapists or nurses. Advocates believe the insurance industry may be shortsighted in imposing arbitrary limitations on the number of treatments. These limitations can have adverse medical consequences for the patient. Patient advocates believe it is more cost effective to pay for lymphedema treatment rather than cover the cost of hospitalization of cellulitis develops.

If an insurance company does not specifically exclude lymphedema coverage, they must cover treatment, providing it is defined as a medical condition. It will be necessary to submit documentation to the company with a statement from your doctor with the medical diagnosis. If you need to provide more information, you should include medical journal articles, outlining a medically accepted treatment program for lymphedema, including skin care, exercise, MLD and daily use of bandages and compression sleeves.

The good news is that progress is being made, albeit slowly. In 1988, there were only 36 treatment centers in the U. S. – today there are 131. The number of schools in North America that trains therapists has increased from two to nine. Political activists – people whose lives have been affected by this condition – are championing the cause.

Websites available for further education about lymphedema include www.lymphnet.org and www.lymphaware.org. A highly recommended book on the subject is “Coping With Lymphedema” by Joan Swirsky, R. N. and Diane Sackett Nannery.

Article by Nancy A. McGaan, Trumbull, CT, a breast cancer survivor and LE patient, HotLine Volunteer for Y-Me of Connecticut and member of the Board of Directors of the Circle of Hope Lymphedema Foundation. Edited by Judy Perotti, director of Patient Services. May 2001. ⌘

Clinical Trials

by Arlyne Draper, Y-Me San Diego



Almost two years ago, I approached Senator Dede Alpert in San Diego to urge her to introduce legislation that would mandate that insurance companies pay for routine patients' costs while participating in a clinical trial.

This idea came to me as

I spoke to one of our medical advisors, Dr. Barry Meisenberg, who had moved to the University of Maryland. Barry worked diligently and he and others were instrumental in the passage of the clinical trial legislation in Maryland. The language of this legislation was the example that I presented to Senator Alpert.

Senator Alpert passed on my suggestion to Assemblyman Howard Wayne and, back then, he introduced AB591, a very similar legislation to the Maryland law.

All through the year 2000, the California Breast Cancer Organizations (CABCO) and its member organizations, including Y-ME San Diego, worked with Assemblyman Wayne, educating our representatives in Sacramento, including the governor and his staff. Y-ME San Diego members visited the governor's office, along with CABCO members several times and we established a close relationship with his staff. Despite our efforts and hard work, AB591 did not make it out of suspense at the end of that legislative year.

Our meetings with the governor's staff had very positive results though. The governor wrote a letter to the California Senate expressing his interest in drafting a comprehensive bill for cancer clinical trials that would cover patients' costs enrolled in such trials.

Here are excerpts from his letter:

“Clinical trials represent the leading edge in our fight against cancer and other deadly diseases, and are often a last hope for thousands of men and women who die of these diseases each year. I believe that health plans should cover the cost of routine patient care for enrollees participating in clinical trials – in fact, it should not even be controversial. Clinical trials are not only the path toward a cure, routine care in a clinical trial is often less costly than care with standard treatment. The fact that many health plans do not cover these costs defies common sense and provides a disincentive for patients to enroll in cancer trials. This disincentive costs lives.

I will continue to do all I can in this fight. I intend to sponsor legislation for introduction the first day of the next legislative session, and I will be requesting swift passage.”

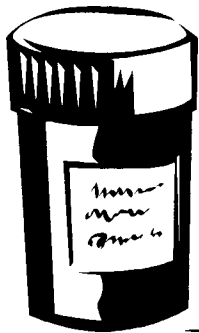
– Governor Gray Davis

We need your help. We must write our California representatives and urge them to support SB37, Health Insurance Coverage for Clinical Trials, authored by Senator Jackie Speier. As you can see, you too can make a difference. If we want change in our communities and in our state, we must all get involved in the political process. ⌘

If you would like to volunteer for Between Women projects, please call Linda Cady at 344-5019. Volunteers are always welcome and we encourage everyone to help in this worthwhile endeavor. ⌘

Cancer Drug Enters Expanded Human Trials

by Richard Saltus, *The Boston Globe* c. 2001



A fast-rising cancer drug from the laboratory of Dr. Judah Folkman has been moved into expanded human trials and given a commercial name, signaling its swift progress in human studies.

The drug, until now called 2-methoxyestradiol, or 2ME2, has been named Panzem by its corporate sponsor, EntreMed Inc. of Rockville, MD, which is developing other Folkman drugs including Endostatin and Angiostatin.

Like those drugs, Panzem is an angiogenesis inhibitor – it fights cancer by cutting off the blood supply that tumors need to grow and spread. But unlike those drugs, Panzem also strikes directly at tumor cells, completing a one-two punch.

And it has another advantage: it can be given in pill form, while other angiogenesis inhibitors are proteins delivered by injection.

“Given the speed at which this exciting anticancer agent is moving through our clinical program, it is time to establish a clear brand name for this product candidate,” said Dr. Joanna Horobin, an EntreMed vice president.

Panzem has been in testing at the University of Indiana Medical Center for treatment of advanced breast cancer, and at the Mayo Clinic in Minnesota for multiple myeloma.

EntreMed said the drug will go into Phase II testing for prostate cancer at Indiana University and the University of Wisconsin, involving a total of 32 patients.

Separately, the drug is undergoing testing for prostate cancer at several centers under the aegis of Cap CURE, an organization founded by former junk bond financier Michael Milken. ⌘

Antidepressants and Hot Flashes

Internet – NCI Cancertrials

A study by Charles Loprinze, M.D., of the Mayo Clinic Cancer Center in Rochester, Minnesota, showed the benefits of antidepressants in relieving hot flashes. Effexor (Venlafaxine) greatly reduced hot flashes in 62 percent of the 229 study participants.

In the study, women were given 75 milligrams per day, while women taking Effexor for depression took 150 milligrams per day. Increasing the dosage in the study did not have any effects on the hot flashes. ⌘



Definition of Cure

Deborah Collyar, PAIR Listserv



It is important that we get the medical world to understand the need to stop using the word “cure” until we can honestly count on the public definition in all conversations with patients. So how can we do this?

When the subject of “cure” comes up, ask the person to define the word “cure.” They will probably hem and haw and then say it means “five years’ survival.”

Politely explain how the public and patients hear the word and ask them to use “remission” instead. They can even say “there is a chance for permanent remission,” but not “cure.” ⌘

After the Storm

by Janet S. Tiger

I used to sail when I was younger. Now my only contact with boats is my oncologist - who loves to sail. But though I never faced a stormy sea

(I stayed safely in the bay), I now have faced a greater storm – a storm of the soul

With waves as high as heaven, the cells of cancer the spray in my face. And yet, through it all,

I knew there would be a calm, a peace, a healing of the sea. For I have faced this ocean of illness, and I have won.

So now I watch others sail the stormy seas
And I can only throw them a lifeline of words
To help them up the face of waves
As towering as the sky.

And I watch others, the nurses who helped me,
The lighthouses of love,
To guide the next sailors
Into the safe haven of wellness.

And I thank them. For all you do . . . this poem's for you!

Janet S. Tiger is the author of “A Mother’s Garden of Verses.” Her e-mail address is janetstiger@mail.com. ⌘



2001 Calendar of Events

- January 2 – Monthly Support Meeting
February 6 – Monthly Support Meeting
February 25 – 1st Christian Church Cancer Workshop
March 6 – Monthly Support Meeting
March 8 – Housing Authorities Cancer Latina Workshop
March 8-10 – Regional Y-Me Conference, San Diego
April 3 – Monthly Support Meeting
April 30 – Assembly of God, Brawley, Cancer Workshop
May 5 – Monthly Support Meeting
May 5-9 – Washington, D.C., Advocacy Conference
May 8 – Posada Del Sol Cancer Latina Workshop
May 16 – Teen Presentation BUHS Pregnant Minors
May 17 – El Centro Rotary Presentation, Linda Cady
May 20 – Central Baptist Church Cancer Workshop
May 24 – 2nd Baptist Church Cancer Workshop
May 27 – Our Lady of Guadalupe, Calexico, Cancer Workshop (2 sessions English/2 sessions Spanish)
June 5 – Monthly Support Meeting
July 3 – Monthly Support Meeting
July 25-28 – National Y-Me Conference, Chicago

In addition to monthly Board meetings January-May, biweekly board meetings through September for the success of the annual Luncheon Benefit.

New Attitudes

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New Attitudes, a **free** educational publication made available to all interested residents of the Imperial Valley, is scheduled to be published and circulated four times a year – in March, June, September and December. Direct all questions and/or comments about this newsletter to Linda Cady.

NOTICE

Are you a breast cancer survivor? Do you know someone or have a loved one who is a breast cancer survivor? *Between Women* breast cancer survivors **need** and **want** to be in contact with you or with them! Call Linda Cady at 344-5019 with names and addresses to receive a **free** copy of *New Attitudes*.

The goal of *New Attitudes* is to provide Imperial Valley women with vital information on the prevention and successful treatment of breast cancer. **♀**



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