Withdrawal/Redaction Sheet
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. list	Updated MMI Corporate List [Personally Identifiable Information] [partial] (3 pages)	10/20/1998	b(6)
002. list	Revised [Personally Identifiable Information] [partial] (1 page)	09/10/1998	b(6)

COLLECTION:
Clinton Presidential Records
First Lady's Office
Jennifer Klein
OA/Box Number: 13530

FOLDER TITLE:
Breast Cancer/Mammography 1998 [2]

2014-0536-S
kc1551

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
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P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.
PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

b(1) National security classified information [(b)(1) of the FOIA]
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WHSO Layout Draft 2
a/o 10/19/98; L. Schwartz, 5:55 p.m.

BREAST CANCER PREVENTION EVENT
Wednesday, October 21, 1998
East Room

EV Gate Opens:	3:15 p.m.		
Invite Time:	3:30 p.m.		
Principal Time:	**4:00 p.m.**	**Brief**	**Elevator, State Floor**
	4:05 p.m.	**Meet**	**Blue Room**
	4:15 p.m.	**Event**	**East Room**

Approx. 180/Open Press/Business Attire
10 Social Aides

SET UP NOTES GROUND FLOOR: *coat check in family theater.*
GRAND FOYER/STATE FLOOR: *string combo with piano in Grand Foyer*
BOOKSELLERS: *one table with cloth for distribution of two packets from the National Cancer Institute for guests on departures.*
EAST ROOM/EVENT*: 10x16 stage at gold curtain; Toast lectern in East Room; WHCA Announce from Blue Room; water at podium; 2 Press risers on both sides of cross hall doors; Breast Cancer Action Plan on chairs.*
BLUE ROOM MEET*: furniture removed from Blue Room for meet and greet; WHCA announce for program; screens (t) up between parlor rooms (t).*

3:10 p.m. IN PLACE TIME

3:15 p.m. East Visitors Gate opens and guests proceed to the State Floor and are seated in the East Room.

3:30 p.m. Participants from the OEOB Roundtable (t) are escorted by S.O.S. U.S.S.S. to the North Portico and proceed to take their seats in the East Room.

4:00 p.m. **THE FIRST LADY** arrives at the elevator on the State Floor and is briefed.
Contact: Jennifer Kleig

4:05 p.m. **THE FIRST LADY** proceeds to the Blue Room to meet event participants.

Blue Room Participants

Event Participants:
Secretary Shalala
Research Scientist tbd
Fran Visco, President of the National Breast Cancer Coalition

Others:
Richard Clausner - National Cancer Institute
TBD - Center for Disease Control
TBD - Food and Drug Administration
TBD - National Institute of Health
Sue Baily - Acting Assistant Sec for Health Affairs at Department of Department
Wanda Jones - Office on Women's Health
Medicare Mammography Initiative Corp Reps - approx. 10

4:10 p.m. **THE FIRST LADY** is announced into the East Room accompanied by Secretary Donna Shalala, Fran Visco, The President of the National Breast Cancer Coalition and others tbd.

PROGRAM BEGINS

THE FIRST LADY makes substantive remarks and introduces Fran Visco, The President of the National Breast Cancer Coalition.

Fran Visco, The President of the National Breast Cancer Coalition makes remarks and introduces Scientist TBD.

Scientist TBD makes remarks and introduces Secretary Shalala.

Secretary Shalala makes remarks.

THE FIRST LADY returns to the podium to thank guests for coming and departs.

Guests depart East Gate.

BREAST CANCER EVENT (10/21)
Seating

__ pink reserved - survivors

__ blue reserved - blue room guests

____ MOC cards

Cynthia Dailard 10/21/98 10:51:14 AM

Record Type: Record

To: Jennifer L. Klein/OPD/EOP

cc:

Subject: contraceptives

Due to a provision sponsored by Rep. Nita Lowey and Senator Harry Reid, the 1.2 million women of childbearing age who participate in the federal employees health benefits program will now have greater access to prescription contraceptives. This important benefit will promote the reproductive health of women, and help lower rates of unintended pregnancy and abortion.

(I know that Reid would appreciate his name being mentioned -- given his tough reelection bid -- if there is time and it is appropriate)

HHS NEWS

DRAFT #276

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
October XX, 1998

HHS Press Office
(202) 690-6343
NCI Press Office
(301) 496-6641

BREAST CANCER ~~PREVENTION~~ STUDY ~~OF TAMOXIFEN AND RALOXIFENE~~ TO OPEN IN EARLY 1999 - SECRETARY SHALALA ALSO NOTES OUTREACH EFFORTS DURING BREAST CANCER AWARENESS MONTH

HHS Secretary Donna E. Shalala announced today that the ~~largest ever~~ most ambitious breast cancer ~~chemoprevention~~ to reduce a woman's risk of breast cancer clinical trial is scheduled to open at an estimated 400 sites across the United States and Canada ~~early~~ in 1999, pending approval by the Food and Drug Administration. The Study of Tamoxifen and Raloxifene, or STAR, will include ~~22,000~~ more than 20,000 postmenopausal women at increased risk of breast cancer and builds upon the success of the Breast Cancer Prevention Trial, which showed that of high-risk women taking the drug tamoxifen reduced their chance of developing breast cancer by 49 for breast cancer percent.

STAR will ~~determine whether~~ evaluate the benefits and risks of raloxifene, a drug similar to tamoxifen, ~~is also effective~~ in ~~preventing~~ decreasing the risk of breast cancer in women who have not had the disease, ~~and whether the drug has benefits over tamoxifen, such as fewer side effects~~. Raloxifene was recently approved by the Food and Drug Administration as an osteoporosis prevention drug for postmenopausal women.

"Early detection remains our most powerful weapon in the war against breast cancer and I am proud of the achievements we have made since creating the National Action Plan on Breast Cancer in 1993," said Secretary Donna Shalala. "But we need to continue to get the message out that 93 percent of breast cancer cases are successfully treated when detected early. That's the difference between a breast cancer survivor, and a statistic."

DRAFT--DRAFT--DRAFT

DRAFT

#276

Tamoxifen, a drug used for more than 20 years to treat breast cancer patients, was the focus of the Breast Cancer Prevention Trial (BCPT), a study of over 13,000 women at high risk of breast cancer and the first such large-scale ~~breast cancer prevention~~ study in North America. In April 1998, BCPT researchers released the initial study results about 14 months earlier than expected due to the large benefit of tamoxifen.

In addition to reducing breast cancer incidence by almost half, tamoxifen reduced the number of bone fractures of the hip, wrist, and spine. The drug did, however, increase the women's chances of three rare, but life-threatening health problems, endometrial cancer (cancer of the lining of the uterus), blood clots in large veins, and blood clots in the lung. Women under age 50 appeared to suffer no excess risk of serious effects from tamoxifen.

Shalala also noted the ~~A~~dminstration is using Breast Cancer Awareness Month to highlight the fact that for women age 50-69, having regular mammograms can reduce the chance of death from breast cancer by one-third or more. Despite the potential benefit, 33 percent of women ages 50-64, and 45 percent of women age 65 and older reported not receiving a mammogram during the past two years. Breast cancer is the most commonly diagnosed cancer, and the second leading cause of cancer deaths among American women. This year alone, another 180,000 cases of breast cancer will be diagnosed, and some 44,000 women will die from the disease.

? Not true — Lung cancer

Women participating in STAR, ~~who must be age 35 or older and postmenopausal~~, must be at increased statistical risk of breast cancer, as determined by factors such as their age, family history of breast cancer, personal

- More -

DRAFT--DRAFT--DRAFT

DRAFT

medical history, age at first menstrual period, and age at first live birth. ~~They~~ Woman will be randomly assigned to receive either ~~20 mg of~~ tamoxifen daily or ~~60 mg of~~ raloxifene daily ~~for five years~~. They will receive ~~close~~ careful follow-up examinations, including a mammogram, physical exam, and gynecologic exam, on a regular basis ~~for at least 7 years~~.

The National Surgical Adjuvant Breast and Bowel Project (NSABP), a National Cancer Institute (NCI)-sponsored research network based in Pittsburgh, will run the trial. NSABP has already selected the 193 main institutions who will participate in STAR, including sites in 48 states, 6 Canadian provinces, the District of Columbia, and Puerto Rico. These 193 institutions will form networks with other local physicians, creating an estimated 400 active centers participating in the trial.

The Clinton Administration has responded to the significant threat posed by breast cancer with increased efforts in research, prevention and treatment. HHS Secretary Donna E. Shalala convened a conference in December 1993 to establish a National Action Plan on Breast Cancer, which has awarded more than $9 million in grants for 99 innovative research and outreach projects. At the same time, spending on breast cancer ~~has~~ research at HHS's National Institutes of Health has increased from $237 million in FY 1993 to $XXX million in FY 1999, an increase of XX percent. **[ASMB TO PROVIDE UPDATE.]**

In 1995, First Lady Hillary Rodham Clinton launched a campaign urging older women to obtain mammograms, and, in particular, to promote use of Medicare coverage for mammography. In

DRAFT
#276

addition, President Clinton proposed, and Congress adopted, the expansion of Medicare coverage to help pay for annual mammograms for all Medicare beneficiaries age 40 and over. This new benefit became available on ~~January~~ Jan. 1, 1998. MQSA?

Women who wish to be put on a mailing list for information about STAR can do so by Internet on the NSABP homepage (http://www.nsabp.pitt.edu), by mail to NSABP, Box 21, Pittsburgh, ~~PA~~ Pa. 15261, or by fax to NSABP at (412) 330-4660.

###

Note: HHS press releases are available on the World Wide Web at: http://www.hhs.gov.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Melissa T. Skolfield
Assistant Secretary for Public Affairs
Phone: (202)690-7850 **Fax: (202)690-5673**

To: Jen Klein

Fax: _____ Phone: _____

Date: _____ Total number of pages sent: 2

Comments:

START clinical trial.

Vicki Ross-Vasey

200 Independence Avenue, S.W., Bldg. HHH, Room 647-D, Washington, D.C. 20201

TO: Jen Klein
Sarah Bianchi

FROM: Vicki Rivas-Vazquez VRV

RE: STAR Trial

FDA is extremely concerned about the definition of the STAR trial. FDA does not want to use the word "prevention" in describing the trial. They want us to use the following phrases when talking about the trial:

"the most ambitious breast cancer clinical trial to reduce a women's risk of breast cancer"

"the largest ever clinical trial of a drug to reduce a women's risk of breast cancer"

The STAR clinical trial " will evaluate the benefits and risks of the drug raloxifene in reducing the risk of breast cancer among women at increased risk of breast cancer."

According to Lorrie McHugh, if describing the clinical trial "OF A DRUG" is not used, then you need to refer to the trial as "the most ambitious."

Please call Lorrie in the morning, if you have any questions.

Barbara D. Woolley
10/20/98 04:13:02 PM

Record Type: Record

To: See the distribution list at the bottom of this message

cc:
Subject: 4 names for BC Event -

These are the women for reserved seating and for Mrs. Clinton to mention in speech. Christy has 3 stories, holding on 1 on Zora Brown.

Jean Camak, Washington, DC
Alfreda Elzie, Washington, DC
Hazel Parago (Pa - rah - go), New Castle, Delaware
Zora Brown, Washington, DC

Message Sent To:

Laura D. Schwartz/WHO/EOP
Kim B. Widdess/WHO/EOP
Neera Tanden/WHO/EOP
Christine N. Macy/WHO/EOP
Sarah A. Bianchi/OPD/EOP
Jennifer L. Klein/OPD/EOP

Clinton Presidential Records
Digital Records Marker

This is not a presidential record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

This marker identifies the place of a publication.

Publications have not been scanned in their entirety for the purpose of digitization. To see the full publication please search online or visit the Clinton Presidential Library's Research Room.

Booklet, "Campaign: Vote Breast Cancer," 24 pages

CAMPAIGN: VOTE BREAST CANCER

1998 Voting Record

NBCC

NATIONAL BREAST CANCER COALITION

Breast cancer advocacy at work

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[001]

Barbara D. Woolley
10/20/98 12:09:54 PM

Record Type: Record

To: See the distribution list at the bottom of this message

cc:

Subject: Updated MMI Corporate List - BC Event Tomorros

Representatives Coming to Medicare Mammography Initiative - October 21, 1998

Dagmar T. Farr
Food Marketing Institute
9819 Newhall Road
Potomac, MD 20854
(b)(6)

Jill Froula
American Greetings
One American Rd
Cleveland OH, 44144
(b)(6)

Rebecca Snead, R.Ph.
Virginia Pharmacists Association
5501 Patterson Avenue Ste. 200
Richmond, VA 23226
(b)(6)

Barbara Lardy
American Association of Health Plans
1129-20th Street NW
Washington DC
(b)(6)

James P. Schlicht
Zenecca
1250 Eye Street, NW Ste 804

[001]

Washington DC 20005
(b)(6)

Karen Miller
Zenneca
(b)(6)

Richard Dorff
President, Florida Association of health Maintenance Organizations, Inc.
1415 Piedmont Drive
Tallahassee, FL 32312-2944
(b)(6)

Veronica Jacques
Direct Selling Association
1666 K Street, NW #1010
Washington DC 20006
(b)(6)

Phil Schneider
Managing Director, Public Affairs
National Association of Chain Drug Stores
413 North Lee St.
Alexandria, VA 22313
(b)(6)

Donna Rape
Division Sales Manager
Avon Products, Inc.
2100 Ogletown Road
Newark, DE 19711
302-453-7811
(b)(6)

Homer Pearce
Eli Lilly, Inc.
(b)(6)

[001]

Freda Lewis-Hall
Eli Lilly, Inc.
(b)(6)

Irene M. Brandt
Eli Lilly, Inc.
(b)(6)

David M. Hendler
Director, Retail Operations
1-800-FLOWERS
73 Carteret St.
West Orange, NJ 07052
(973) 736-1499
(b)(6)

Nancy C. Yedlin
Pitney Bowes
203-351-6714
(b)(6)

FAX TRANSMISSION

To: Jen Klein **Date:** 10/20

Fax #: 202/45 69412 **Pages:** 8 , including this cover sheet

From: Office of Public Affairs
Food and Drug Administration
Lorrie McHugh-Wytkind
Associate Commissioner for
Public Affairs

15-05 Parklawn, HFI-1
301-827-6250(office phone)
301-594-6004 (fax)
301-443-3819 (fax)

COMMENTS:

5 Year Report on Breast Cancer
Internal Questions & Answers
DRAFT
(October 21, 1998)

General:

Q. We hear about different scientific progress/investigations/trials every day - are we close to a cure? Does the Administration believe we will find a preventive drug or cure soon?

A. In recent years, intensive research into all aspects of breast cancer has led to a flurry of important new discoveries. Scientists understand now more than ever before how a healthy breast cell becomes cancerous, how breast cancer spreads, and why some tumors are more aggressive than others. We are having increasing success in translating these discoveries into therapies that improve cancer-free survival and improve the quality of life for those continuing to live with the disease and into more refined technologies for detecting and diagnosing breast cancer.

But, there is still much work to be done to remove the threat of breast cancer from women's lives. This nation's investment in cancer research and carefully conducted basic research and clinical trials helps make each advance possible, bringing us closer to an end to this disease.

Q. What are the latest studies on incidence and mortality on breast cancer? Is there a direct correlation between Administration's increased funding for research and results?

A. From 1991 to 1995, overall breast cancer incidence rates have leveled off after being on the increase for nearly two decades. This decline was most evident for white and Hispanic women. Breast cancer death rates dropped 1.9 percent per year in white and Hispanic women in the same time frame.

Perhaps most encouraging is that incidence of advanced breast cancers (Stage III and IV), which have the highest mortality rates, have dropped by over 11 percent in Whites and about 18 percent in Black women over the last ten years.

Increased funding for cancer research makes it possible for cancer researchers to seize extraordinary opportunities to further the progress that is brought about by previous research successes. It also speeds the translation of important new discoveries into the daily practice of medicine that will benefit everyone.

Q. What are general guidelines for women and breast cancer screenings?

The National Cancer Institute recommends that women in their forties or older get screening mammograms on a regular basis, every 1 to 2 years.

Women who are at increased risk for breast cancer should seek medical advice about when to begin having mammograms and how often to be screened. (For example, a doctor may recommend that a woman at increased risk begin screening before age 40 or change her screening intervals to every year.)

Q. Will more mammograms cause more invasive and possibly unneeded procedures for older women?

A. A recent study suggested that women age 70 and older had a significant number of follow up procedures after abnormal mammograms. However, other studies would need to be done to determine the significance of this finding. A woman's chance of developing breast cancer in her lifetime rises significantly after age 60, so no woman should consider herself too old for regular screening mammograms.

Specific:

Q. We've heard so much about tamoxifen this past year - is this the one drug that is better than the rest?

A. The Breast Cancer Prevention Trial, which showed tamoxifen can reduce breast cancer by half, was not an end, but a promising beginning that tells us that it is possible to ~~prevent~~ decrease a woman's risk of breast cancer. Tamoxifen has shown a major benefit for high-risk women, but may cause serious side effects. Researchers are already creating and testing a second generation of breast cancer prevention agents, such as raloxifene, which may help prevent the disease without some of tamoxifen's potential side effects. That is why we are initiating the STAR trial.

Q. How do the federal coordinating committee and the national action plan complement each other?

Q. How do these clinical trials work? Is there FDA approval immediately following clinical trials like the STAR trial?

A. The goal of clinical trials is to find out whether, in the case of the STAR trial, cancer preventive agents--are safe and effective. A clinical trial is one of the final stages of a long and careful cancer research process. The studies involve thousands of participants, and take years to complete. Researchers follow rigorous guidelines and patient safety is monitored

closely throughout the entire process. Results from clinical trials are published in scientific journals and analyzed through a peer-review process. If the trial results indicate a significant benefit, researchers submit a new drug application. The clinical trials data is then submitted to FDA for review.

Example: This was the recent process in the approval of tamoxifen as a preventive treatment for women with high risk of breast cancer.

Q. **What significance does the STAR preventive trial have in the search for a cure to breast cancer.**

A. As we continue our quest for a drug to help prevent breast cancer for all women, we can mark the discovery and development of tamoxifen as a major milestone that established a new avenue of prevention research that should continue to foster prevention discoveries and successes in the future. The STAR trial will build on the success of the tamoxifen study , and determine whether raloxifene, a drug similar to tamoxifen, is also effective in preventing breast cancer in women who have not had the disease, and whether the drug has benefits over tamoxifen, such as fewer side effects.

The breast cancer prevention trials are part of a comprehensive, broad range approach to breast cancer research into finding effective ways to detect, treat, cure, and ultimately prevent the disease.

Q. **Should all women take tamoxifen?**

A. Tamoxifen is only appropriate for women with an increased risk of breast cancer, and the drug may not be right for every women at high risk. In September, NCI made available a computer-based tool to help health professionals project a woman's individualized estimate of breast cancer risk, allowing a woman and her health care provider an opportunity to discuss the potential benefits and risks of taking tamoxifen.

Q. **How can a woman join the STAR trial?**

A. Women can be put on a mailing list to receive information about STAR by Internet (http://www.nsabp.pitt.edu), by mail (National Surgical Adjuvant Breast and Bowel Project, Box 21, Pittsburgh, PA 15261), or by fax (412-330-4660). Once the trial has begun, women can get information from NCI's Cancer Information Service at 1-800-4-CANCER and the NCI web site for clinical trials information (http://cancertrials.nci.nih.gov).

Q. **How much will the STAR trial cost?**

A. (NCI will respond)

The National Breast Cancer Coalition
a grassroots advocacy effort

FAX COVER SHEET

TO: Jennifer Klein

FAX # 456-2878

FROM: Fran Visco

DATE: 10/16 BH ACCOUNT # 13

NUMBER OF PAGES (including cover sheet) 3

COMMENTS: Please see attached.

D' Am.

NATIONAL BREAST CANCER COALITION

« a grassroots advocacy effort »

October 16, 1998

Jennifer L. Klein
Domestic Policy Council
Executive Office of the President
Second Floor, West Wing
1600 Pennsylvania Avenue, N.W.
Washington, D.C. 20500

Dear Jennifer,

I understand that the First Lady would like to focus on the future of breast cancer at the October 21 event. I wanted to give you a few comments on that issue, at least in terms of breast cancer research.

One study that you are contemplating highlighting is the tamoxifen/raloxifene trial. This is extremely problematic. Firstly, the tamoxifen "prevention" trial that this new study is based upon did not answer the ultimate outcome: whether tamoxifen actually prevents breast cancer and does so without causing more deaths from other causes. The fact that the trial was closed prematurely foreclosed our ever getting that answer, since the women are no longer randomized to a placebo. As you know, the FDA's advisory committee struggled with the data and ultimately agreed to advise approval of the drug for an as yet undefined group of women, but certainly within the group who ultimately enrolled in the trial, and not for prevention, but for "reduction in short term incidence of breast cancer." There are so many issues raised by this trial, and the data must be carefully analyzed before we can move forward. We must look at exactly which group of patients received any benefit at all and the nature of that benefit. For example, many believe that this is actually an early treatment effect in a group of high risk women. The cancers that are being delayed are small, ER-positive, node-negative breast cancers: the "nicest" type of breast cancer. And at what cost? We just don't know.

To compound this situation, the design proposed for the new tamoxifen/raloxifene trial is flawed, and is something that will be strongly opposed and publicly exposed by many. There are many in the scientific and advocacy world who believe that this trial is badly designed in that it lacks a placebo arm. It seems unwise to use the upcoming event to focus the attention of the women's health community on these problematic and unfinished studies.

More exciting to the advocacy community is the recent approval of Herceptin, not because of the data on its affect on mortality, but because it is a targeted therapy, a proof of principle that will bring us to the next level of research in breast cancer. The story of how we got there is quite wonderful, showing a public-private partnership that worked.

Many areas of prevention that are not toxic are being examined. For example, Leslie Bernstein's work at USC on the association between physical activity and breast cancer, an area that was examined by the National Action Plan on Breast Cancer, is quite exciting. There are new studies and questions being asked about diet and breast cancer.

I am hoping to convince you that there are great stories about the future that should be told, rather than focusing on one trial that is quite controversial. I know that industry and NCI are pushing that trial, but that should not be enough to highlight a complex situation to the public at the risk of giving misleading information to healthy women.

Let's talk.

Sincerely,

Fran Visco

Frances M. Visco
President

To: Elizabeth Summy@IOS.IO
From: "Burklow, John (NCI)" <burklowj@occ.nci.nih.gov>
Cc:
Bcc:
Subject: FW: Whitehouse speakers
Attachment: Headers.822
Date: 10/16/98 3:05 PM

- Dr. Klausner rec

Liz-- Nancy Davidson MD Prof at Johns Hopkins 410/955 8489

Here are the names we've come up with so far. I also want to add Lori Goldstein, M.D., from Fox Chase (Philly). She runs the breast cancer research
programs there and is supposed to be a really good speaker.

I'm getting more background on each of them.

John B.

Here's the list of potential speakers for consideration by the Whitehouse.

1. Bernard Fisher, MD, Former Chairman and current Scientific Director of the NSABP. University Professor, Allegheny University of Health Sciences

412/330-4410 or 412/330-4412 for his executive secretary Carol Leech

2. Mary Daly, MD, Fox Chase Cancer Center, Philadelphia, PA

Office Number 215/728-2791 Her secretary Susan Steinberg
Pager Number 215/374-2006
Last resort, contact Joan James at 215/728-4750 or pager # 215/374-2051

Office number 202/806-7697

3. Claudine Isaacs, MD, Georgetown University Cancer Center

Dr. Isaacs will be out of her office on Monday, October 19 and Tuesday October 20. Her office staff can reach her by page. Contact either Eva Murray at 202/687-2103, or Jackie William at 202/687-2108

Let me know if you require any other details.

Lori
f

B.C. event
breakfast
FYI
Barb.

To: Vicki Rivas-Vazquez@ASPA
From: "Burklow, John (NCI)" <burklowj@occ.nci.nih.gov>
Cc:
Bcc:
Subject: FW: STAR centers list
Attachment: STARcen.wpd,Headers.822
Date: 10/15/98 8:52 AM

Vicki--

Here is a listing of the 193 institutions by state (the NSABP release listed them alphabetically, which wasn't very user-friendly).

John B.

Alphabetical by state. US and Canada separated.

<<STARcen.wpd>>

October 1998

Study of Tamoxifen and Raloxifene (STAR) Selected Centers List

CCOP = Community Clinical Oncology Program, a network that provides the infrastructure to link community cancer specialists and primary care physicians with larger research networks, such as cooperative groups and cancer centers.

MBCCOP = Minority-based Community Clinical Oncology Program

United States

Alabama

Comprehensive Cancer Institute, Huntsville
University of Alabama at Birmingham, Birmingham
University of South Alabama, Mobile (MBCCOP)

Arizona

Arizona Cancer Center, Tucson
Cancer Resource Network, Mesa
CCOP, Greater Phoenix, Phoenix
Mayo Clinic - Scottsdale, Scottsdale (CCOP)

Arkansas

Arkansas Cancer Research Center/Universityof Arkansas for Medical Sciences, Little Rock

California

Bay Area Tumor Institute, Oakland (CCOP)
Cedar-Sinai Health System, Los Angeles
City of Hope National Medical Center, Duarte
InterCenter Cancer Research Group, Palm Springs
Kaiser Permanente, Northern California, Oakland
Kaiser Permanente, San Diego, San Diego
Loma Linda University Cancer Institute, Loma Linda
Los Angeles Oncologic Institute, Los Angeles
Naval Medical Center & Office of the Lead Agent, TRICARE Region Nine, San Diego
NCCC UCSF Stanford, Union City
San Diego Endocrine & Medical Clinic, San Diego
San Gabriel Valley Clinical Oncology Research Program, Pasadena
Santa Rosa Memorial Hospital, Santa Rosa (CCOP)
Scripps Memorial Hospitals Stevens Cancer Center, La Jolla

St. Mary Medical Center, Long Beach
Sutter Health, Sacramento
UCD Cancer Center, Department of Surgical Oncology, Sacramento
UCLA Cancer Prevention Network, Los Angeles
UCSD Cancer Center, La Jolla
University of California, Irvine Medical Center, Orange
USC/Norris Comprehensive Cancer Center, Los Angeles

Colorado

Colorado Cancer Research Program, Denver (CCOP)

Connecticut

Connecticut Task Force, Hartford
Yale Cancer Center, New Haven

Delaware

Christina Care Health Services, Wilmington (CCOP)

District of Columbia

Georgetown University/Lombardi Cancer Center, Washington, DC
Howard University Cancer Center, Washington, DC

Florida

Baptist Regional Cancer Institute, Jacksonville
Clinical Research Center of South Florida, Stuart
H. Lee Moffitt Cancer Center & Research Institute, Tampa
South Florida STAR Group, Miami Beach
West Florida Clinical Research Center, Inc., Pensacola

Georgia

Atlanta Regional CCOP, Atlanta

Hawaii

University of Hawaii/Kuakini Medical Center, Honolulu

Idaho

North Idaho Cancer Center, Coeur D'Alene

Illinois

Cardinal Bernardin Cancer Center, Maywood
Carle Cancer Center, Urbana (CCOP)
Central Illinois, Decatur (CCOP)
Highland Park Hospital, Highland Park
Lynn Sage Breast Center, Chicago

Resurrection Health Care, Chicago
Rush-Presbyterian-St Luke's Medical Center, Chicago
University of Chicago Hospitals, Chicago
University of Illinois at Chicago, Chicago

Indiana

Indiana Community Cancer Care, Inc., Indianapolis
Memorial Hospital of South Bend
Vincent Hospital and Health Care Center, Indianapolis

Iowa

Cedar Rapids Oncology Project, Cedar Rapids
Iowa Oncology Research Association, Des Moines (CCOP)
University of Iowa Hospitals and Clinics, Iowa City

Kansas

CCOP, Witchita, Witchita
University of Kansas Medical Center, Kansas City

Kentucky

Alliant Hospital Inc., Louisville
Baptist Hospital East, Louisville
James Graham Brown Cancer Center, Louisville
University of Kentucky Consortium, Lexington

Louisiana

Alton Ochsner, New Orleans (CCOP)
LSUMC/Stanley S Scott Cancer Center, New Orleans (MBCCOP)

Maine

Eastern Maine Medical Center/Cancer Care of Maine, Bangor

Maryland

Baltimore-Washington Regional STAR Clinical Center, Baltimore
Greenebaum Cancer at the University of Maryland, Baltimore
Johns Hopkins Breast & Ovarian Surveillance Center, Baltimore

Massachussets

Berkshire Hematology Oncology, P.C., Pittsfield
Beth Israel Deaconess Medical Center, Boston
Boston Medical Center, Boston
Dana Farber Cancer Institute, Boston

Michigan

Barbara Ann Karmanos Cancer Institute, Detroit
CCOP, Ann Arbor, Ann Arbor (CCOP)
CCOP, Grand Rapids, Grand Rapids (CCOP)
CCOP, Kalamazoo, Kalamazoo (CCOP)
Michigan State University, East Lansing
Providence Hospital and Medical Centers, Southfield
University of Michigan Comprehensive Cancer Center, Ann Arbor
William Beaumont Hospital Breast Care Center, Royal Oak

Minnesota

CCOP, Duluth, Duluth (CCOP)
Centracare Clinic, St. Cloud
Hennepin Consortium, Minneapolis
Mayo Clinic, Minneapolis
Metro-Minnesota, St. Louis Park (CCOP)

Mississippi

North Mississippi Hematology and Oncology Associates, Ltd., Tupelo

Missouri

Breast Care Center at St. Luke's, Chesterfield
Cancer Center at Barnes Jewish Hospital & Washington University School of Medicine, St. Louis
Cancer Research for the Ozarks, Springfield
CCOP, Kansas City
Ellis Fischel Cancer Center, Columbia
St Louis-Cape Girardeau, St Louis (CCOP)

Montana

Montana Cancer Consortium, Billings (CCOP)

Nebraska

Creighton University Cancer Center, Omaha
Methodist Cancer Center, Omaha

Nevada

South Nevada Cancer Research Foundation, Las Vegas (CCOP)

New Hampshire

Dartmouth-Hitchcock Medical Center, Lebanon

New Jersey

Cancer Institute of New Jersey, New Brunswick
CCOP, Northern New Jersey, Hackensack
Saint Barnabas Health Care System Consortium, Newark
University of Medicine & Dentistry of N.J., Newark

New Mexico

University of New Mexico Cancer Research &Treatment Center, Albuquerque

New York

Albert Einstein Comprehensive Cancer Center, Bronx
Bassett Healthcare, Cooperstown
Cancer Center at Glen Falls Hospital, Glen Falls
CCOP, Syracuse, Syracuse (CCOP)
Columbia Presbyterian Medical Center, New York
Memorial Sloan-Kettering Cancer Center, New York
Mid-Hudson Health Cancer Center, Poughkeepsie
Mount Sinai Medical Center, New York
North Shore University Hospital, Manhasset (CCOP)
NYU Medical Center (Kaplan Comprehensive Cancer Center), New York
St. Vincents Hospital and Medical York Medical College, New York
University Hospital, Syracuse
University Hospital & Medical Center SUNY-Stony Brook, Stony Brook
URCC Cancer Prevention Network, Rochester
Western New York STAR Consortium, Buffalo

North Carolina

Duke University Medical Center, Durham
East Carolina University, Greenville
Southeast Cancer Control Consortium, Inc., Winston-Salem (CCOP)
University of North Carolina School of Medicine, Chapel Hill
Wake Forest University School of Medicine, Winston-Salem

North Dakota

MeritCare Hospital, Fargo (CCOP)

Ohio

CCOP, Columbus, Columbus
CCOP, Dayton, Dayton
Greater Cincinnati Collaborative PreventionTrial Group, Cincinnati
Ireland Cancer Center, Cleveland
Meridia Health System/Meridia Cancer Institute, Mayfield Heights
Mount Sinai Center for Breast Health, Beachwood

Ohio State University/Arthur G. James Cancer Hospital, Columbus
St. Mary Medical Center, Long Beach
Summa Health System/Akron City Hospital, Akron
Toledo Community Clinical Oncology Program,Toledo

Oklahoma

CCOP, Oklahoma, Tulsa
OKC NSABP Consortium, Oklahoma City

Oregon

Columbia River Oncology Program, Portland (CCOP)
Oregon Health Sciences University/Oregon Cancer Center, Portland

Pennsylvania

Albert Einstein Cancer Center, Philadelphia
Allegheny Cancer Center Protocol Office, Pittsburgh
Fox Chase Cancer Center, Philadelphia
Geisinger Breast Clinic, Danville
Kimmel Cancer Center at Thomas Jefferson, Philadelphia
Lehigh Valley Hospital, Allentown
Main Line Health, Wynnewood (CCOP)
Mercy Hospital Cancer Center, Scranton
University of Pennsylvania, Philadelphia
University of Pittsburgh Medical Center, Pittsburgh
Western Pennsylvania Cancer Institute, Pittsburgh
York Health System Cancer Center, York

Puerto Rico

MBCCOP, San Juan, Puerto Rico

South Carolina

CCOP, Greenville, South Carolina
Upstate Carolina, Spartanburg (CCOP)

South Dakota

Cancer Care Institute (CCI), Rapid City
Sioux Community Cancer Consortium, Sioux Falls (CCOP)

Tennessee

Baptist Cancer Institute, Memphis (CCOP)
Thompson Cancer Survival Center, Knoxville
University of Tennessee Medical Center at Knoxville
Vanderbilt Cancer Center, Nashville,

Texas

Baylor-Sammons Cancer Center, Dallas
Hendrick Cancer Center, Abilene
Joe Arrington Cancer Research and Treatment Center (JACC), Lubbock
M D Anderson Cancer Network - Tarrant County, Forth Worth, TX
Scott and White Clinic, Temple (CCOP)
Southwest Cancer Center TTUHSC-Lubbock
University of Texas Health Science Center at San Antonio
University of Texas M D Anderson Cancer Center, Houston
UT Southwestern Center for Breast Care, Dallas
Wilford Hall Medical Center, Lackland AFB

Utah

Huntsman Cancer Institute at the University of Utah, Salt Lake City

Vermont

Vermont Cancer Center, University of Vermont, Burlington

Virginia

Virginia Commonwealth University, Richmond (MBCCOP)

Washington

CCOP, Northwest, Tacoma (CCOP)
Fred Hutchinson Cancer Research Center/Puget Sound Oncology, Seattle
Valley Cancer Group, Yakima
Virginia Mason, Seattle (CCOP)

West Virginia

Camcare Health Education & Research Institute, Charleston

Wisconsin

CCOP, Marshfield, Marshfield (CCOP)
Milwaukee Breast Cancer Prevention Project, Milwaukee
University of Wisconsin Hospitals & Clinics, Madison

Canada

Alberta

Cross Cancer Institute, Edmonton
Tom Baker Cancer Centre, Calgary

British Columbia

British Columbia Cancer Agency - UBC Site,Vancouver

Manitoba

Manitoba Cancer Treatment & Research Foundation, Winnipeg

Ontario

Northwestern Ontario Regional Cancer Centre, Thunder Bay
Ottawa Regional Cancer Centre/Ottawa Breast Health Center, Ottawa
St. Michael's Hospital, Toronto
Women's College Hospital, Toronto

Quebec

Centre Hospitalier de l'Universite de Montreal
CHA/Pavillon St-Sacrement, Quebec
Jewish General Hospital, Montreal
Montreal General Hospital, Montreal
Royal Victoria Hospital, Montreal

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Date: September 16, 1998

TO: Neera Tanden 202/456-2878

From: CAROL KRAUSE, Director of Communications
PHS OWH Phone: (202) 205-2551 Fax: (205)205-2631

Hopefully Anna Kindermann of the National Acton Plan has gotten back to you. There was some confusion; there was no 5 year PLAN....simply a long set of recommendations and goals written in 1993. There has been a document produced that is a 5 year accomplishment summary; yet it has not yet been cleared for distribution. Beth (who called you yesterday) thought you were referring to the accomplishments document, which would have required Chief-of-Staff clearance, so she gave you a name in the Chief of staff office.

I am faxing you a summary of the original goals and recommendations, you can also refer to the NAPBC web site (http://www.napbc.org) Perhaps Anna has faxed you the same information, but I wanted to be sure ou got it immediately.

Anna Kindermann is your best source for information on this 401-1170. Sorry for the confusion; please feel free to call me anytime for any women's health information.

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Proceedings

Secretary's Conference to Establish a National Action Plan on Breast Cancer

National Institutes of Health
Bethesda, MD
December 14-15, 1993

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B. Increase participation of breast cancer advocacy groups in health policy decisionmaking.

C. Eliminate unnecessary confusion about breast health issues

D. Make breast health management, diagnosis, treatment, and follow-up care comprehensive, compassionate, widely available, and of high quality

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Appendix A: Registrants' List

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The Secretary's Conference to Establish a National Action Plan on Breast Cancer

December 14-15, 1993
Bethesda, MD

Chair: Donna E. Shalala, Ph.D.
Secretary of Health and Human Services

Co-Chairs: M. Joycelyn Elders, M.D., Surgeon General
Ruth L. Kirschstein, M.D., Deputy Director, National Institutes of Health

Breakout Group Co-Chairs:

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Emory University

Kathy S. Albain, M.D.
Loyola University Medical Center

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Emory University School of Public Health

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We would like to give special recognition to Herbert L. Selesnick, Ph.D., Sterling and Selesnick; the Office of Research on Women's Health, NIH; the National Cancer Institute, NIH; and Cygnus Corporation.

Introduction

Despite progress in reducing mortality from several cancers, breast cancer remains a major cause of death, disability, and reduced quality of life for American women. In 1993 approximately 183,000 women were newly diagnosed with breast cancer, while some 46,000 died of the disease. For all American women combined, the incidence of breast cancer has been increasing while mortality has been relatively constant. Experience varies, however, with different population groups. For example, the incidence of breast cancer for women of all ages combined is higher among whites than African Americans. However, the death rate from the disease is higher among African Americans. Trends also differ by both age and race. For example, white women under 65 have experienced a 7.2 percent decline in breast cancer mortality from 1973 to 1990 while mortality among African-American women has increased 18.7 percent. Deaths from breast cancer among women 65 and above have increased for both whites and African Americans, although the increase for African Americans at about 30 percent has been about twice that of whites, about 14 percent.

These statistics signal a clear need for action. Equally compelling are the individual experiences of women with breast cancer. On October 18, 1993, President Clinton was presented with petitions signed

by 2.6 million Americans asking for "a comprehensive plan to end the breast cancer epidemic." In accepting the petitions, President Clinton announced that the Secretary of Health and Human Services, Donna E. Shalala, would convene a conference in mid-December to develop an approach to a national action plan on breast cancer. The Secretary's Conference To Establish a National Action Plan on Breast Cancer took place on December 14 and 15, 1993, in Bethesda, Maryland, and Washington, D.C.

From its inception, the conference was intended to embrace and involve the full spectrum of individuals, groups, and organizations concerned about breast cancer. To this end, invitations to the conference were extended to 150 representatives from advocacy groups, consumers, private industry, academia, scientific research, the media, and the field of education (see Appendix A for a list of conference participants). These invited participants worked together in a unique and unprecedented partnership that combined scientific and technical expertise with social insights and personal and professional experience and commitment.

The conference format sought to take advantage of this diversity by identifying and placing participants into topic-centered breakout groups (see the agenda in Attachment A). Each of the 10 breakout groups was further enriched by the presence of invited Federal agency representatives and Congressional staff, who came to provide resource information, to listen, and to learn from the deliberations.

Prior to the conference, to give substance and context to the discussions, each invited participant, Federal representative, and Congressional staff liaison received copies of current reports and proposed plans on breast cancer and a compilation of summary information on Federal agency activities related to breast cancer (see the listing of preconference resource information in Attachment B).

Supplementing this body of information was an extensive collection of resource material on breast cancer, which was made available at the conference. This collection, which filled the conference registration area, was a visible demonstration of the vast array of material on breast cancer available from and for the consumer, health care professional, scientist, advocate, educator, and entrepreneur (see the resource materials in Attachment C).

The first day of the conference was devoted to discussions within the 10 breakout groups, each of which was asked to identify actions considered most important to the pursuit of a national strategy on breast cancer. Summations of each group's discussions were presented by the breakout group leaders at the afternoon plenary session. The day after this first session, the co-chairs of the breakout groups met with Secretary Shalala to further refine and elaborate upon the identified action items. Since that meeting, the co-chairs and others have reviewed the draft action plan and their comments have been incorporated.

The resulting document--a compilation of the conference proceedings--is not a background paper, blue ribbon panel report, or Federal proposal. Rather, it is a blueprint, highlighting opportunities to advance and apply knowledge about the causes, diagnosis, prevention, treatment, and ultimate eradication of breast cancer. It also is a catalyst, promoting partnerships among the public, private, and nonprofit sectors to solve problems and coordinate actions related to breast cancer. Finally, it is an operational strategy, setting into motion a dynamic process of sustained collaboration among many involved groups, agencies, and individuals as they formulate and pursue increasingly concerted actions to attack and conquer the devastating disease that is breast cancer.

I. Health Care

Effective health care delivery is critical to reducing morbidity and mortality from breast cancer. In turn, the health care delivery system depends on the effective dissemination of information about breast health and breast care. Responsibility for breast health services is shared by a wide range of participants including consumers, providers, patients, and educators, as well as industry, the media, and the research community. This section identifies five priority areas and corresponding actions that address health care related to breast cancer.

A. Improve access to and utilization of breast health services.

The following actions will help achieve this goal:

- Mandate public health agencies at all levels to provide all women with essential breast health services through service as system providers, coalition builders, data collectors, quality assurance professionals, public educators, health care provider educators, and community organizers.
- Act immediately to establish breast health services as a priority in all relevant programs funded by the Federal Government. Foster partnerships between the agencies of the Federal Government and the private sector.
- Summarize, disseminate, and implement proven strategies for improving access to and use of breast health care, such as providing vouchers for transportation to and from breast health services and using mobile systems to bring such services to those who need but do not have easy access to them.
- Encourage a pyramid system of health care delivery in which physicians lead a collaborative team that gives qualified nurses, other health care professionals, community outreach workers, advocacy groups, and support groups a prominent role in providing care.
- Use community-based organizations and outreach workers as lay advisors, patient advocates, disseminators, and interpreters of breast health information.
- Require federally-funded hospitals and health care centers to screen all women who enter the health care delivery system, and for whom guidelines recommend regular mammography screening, as soon as possible if they have not already received such services, and provide necessary and appropriate follow-up.
- Make clinical breast exams a part of every general physical examination conducted by qualified health care providers.

B. Improve coordination and information management among providers, patients, consumers, organizations, scientists, the media, and other involved groups to disseminate information on breast health and breast health services.

The following actions will help achieve this goal:

Use the full range of electronic media, print media, consumer-oriented publications and interactive multimedia approaches (1) to disseminate research findings to scientists and the general public and (2) to inform both health care providers and consumers about new scientific knowledge.

- Employ community-based and outreach workers to improve, disseminate, and explain breast health information to health care consumers and providers.
- Sponsor conferences and meetings to facilitate a continuing process whereby relevant organizations at the national, regional, and local levels--including consumers and consumer groups--share information on successful approaches to breast health care, develop consensus on needs for improved and new remedial approaches, and mobilize appropriate participant organizations to take action among their constituencies.
- Coordinate breast health educational programs among Federal, private, and voluntary agencies to minimize redundancies and deficiencies in programs and conflicts in messages. Include consumers in the process.
- Provide incentives for employers and schools to participate in comprehensive, on-site breast health programs for employees and students.

- Develop mechanisms for the centralized collection and distribution of existing and available consumer-oriented information on breast cancer. Materials would be drawn from national, state, and local organizations, including private for-profit and nonprofit organizations, voluntary and professional organizations, and academic and medical institutions.
- Utilize targeted survivor presentations to change perceptions about breast health. Work with media to broadcast group-specific survivor messages; evaluate and disseminate results.

C. Increase participation of underserved and at-risk populations in breast cancer programs related to risk factors, early detection, diagnosis, and treatment.

The following actions will help achieve this goal:

- Increase participation of target populations in breast cancer programs. Include, for example, older women, rural women, women of lower socioeconomic status, lesbians, African Americans, Native Americans, Latinos, Asians, Pacific Islanders, and women who have recently arrived in the United States.
- Involve organizations and individuals that have direct access to and a unique understanding of underrepresented and high-risk population groups in targeting and improving education and services related to breast cancer. Provide a broad range of incentives to promote their involvement.
- Develop and disseminate information on breast health care that is tailored to the cultural, educational, and psychosocial characteristics of women and their families. Report this information in multiple languages.
- Increase the number and use of culturally sensitive, large-scale programs among minorities, such as the National Cancer Institute's Cancer Information Service and Centers for Disease Control and Prevention (CDC) community programs.
- Use target audience research and other social marketing techniques to help customize programs and intervention strategies to specific communities and settings. Develop and apply new and innovative techniques for hard-to-reach populations and individuals.
- Involve consumers with relevant cultural and ethnic backgrounds in the development of culturally sensitive breast health information.
- Provide for the funding of mobile mammography units which could increase access to screening among rural and working women.
- Establish community-based comprehensive school health programs to reach young women with breast health messages for themselves and their families. Pilot breast health programs in other education/social settings, such as low literacy and welfare programs, and school health curricula.
- Provide financial and technical support to local community-based programs that target low-utilization groups to assist in program evaluation and expansion, and to coordinate with program planners.

D. Ensure that research results relevant to breast cancer reach community health care providers, patients, consumers, the elderly, and the general public in a timely fashion.

The following actions will help achieve this goal:

- Communicate clinical research results to the involved community, immediate family members, significant others, and clinical trial participants once valid results have been confirmed.

- Establish a registry of ongoing and published clinical trials that is accessible to the public.

- Disseminate and make widely available information on breast cancer research in forms suitable for different audiences (e.g., consumers, providers, and payers). Conduct research to determine the best way to disseminate knowledge among the different populations. Report research results simultaneously to health care providers and consumers.

E. Establish public and private partnerships to enhance breast health education.

The following actions will help achieve this goal:

- Use multi-organization panels, programs, and forums to extend the scope, impact, and credibility of breast health education programs. For example:

  -Involve consumers at all levels in this effort.

  -Create public-private partnerships for educational programs and efforts.

  -Sponsor conferences to educate and involve the media in breast cancer issues and to facilitate breast health education. Enlist private, for-profit and nonprofit businesses and other organizations in this effort.

  -Sponsor conferences in which biomedical, behavioral, and health care researchers can share information with each other and the communities they serve.

  -Incorporate appropriate breast health information into all preventive services, health education programs, and medical and nursing school curricula.

II. Research

Research on the causes and cures of breast cancer is informed by and relies on a substantial foundation of work on basic cellular mechanisms and on other diseases. This foundation is multidisciplinary and is supported by all Federal agencies, institutions, and organizations that support and conduct research. New knowledge about the causes, diagnosis, prevention, and treatment of breast cancer is derived from many approaches and is accelerated through communication about promising areas of exploration and discovery. The following section addresses key objectives in basic, clinical, and epidemiologic research on breast cancer including (1) ensuring that such research addresses the most promising areas of opportunity; (2) sustaining the growth of investigator-initiated studies; (3) attracting, training, and retaining a qualified and diverse body of research investigators; and (4) overcoming barriers to the conduct of research related to breast cancer. The rapid translation of knowledge gained from such research into clinical practice is critical to ensuring that there are practical benefits for patients.

A. Support collaborative multidisciplinary research related to breast cancer.

The following actions will help achieve this goal:

- Identify and foster promising new areas of basic research through interagency, interdisciplinary, and private- and public-sector collaboration.

- Facilitate collaboration among basic, clinical, behavioral, epidemiologic, and health services scientists across disciplines; among affected consumers; and among university, clinical cooperative group, Federal, and industrial investigators.

- Organize and support multidisciplinary research and collaborative efforts, using a wide range of mechanisms which maximize individual and group efforts. Adapt and/or expand innovative models such as the SPORE mechanism currently used by the NIH. Increase the amount of

discretionary funds provided through the SPORE program and develop methods to provide similar discretionary funds outside the SPORE program.

B. Establish comprehensive patient data registries and materials banks as research tools.

The following actions will help achieve this goal:

- Convene a group consisting of clinicians, basic and clinical research scientists, industrial representatives, representatives of the health care industry, consumers, patients, and Federal agency representatives to develop and define requirements for national resource banks for biological materials relevant to breast cancer. The materials banks should: (1) continuously collect and make available paraffin-embedded and fresh frozen samples of malignant and nonmalignant tissues as well as other specimens such as serum, urine, and DNA from women at risk, women diagnosed as having breast cancer, and unaffected women, as requested; (2) ensure access to and the availability of specimens to diverse investigators through a peer review mechanism; and (3) provide data regarding the source of the specimens, such as patients' family medical history, occupational and epidemiologic information, and clinical results.

  Reports and plans should be submitted to the Secretary of Health and Human Services on the establishment of these banks with initiation targeted for Fiscal Year 1995.

- Establish new, comprehensive registries of patient data that are centralized and easily accessible. Their purposes are for studies of etiology, prevention, detection, diagnosis, treatment, and follow-up and surveillance of breast cancer patients. When possible, these patient data registries should be crossreferenced with the materials banks.

C. Increase opportunities for research training in fields related to breast cancer.

The following actions will help achieve this goal:

- Expand and provide diverse opportunities for interdisciplinary research training through such programs as the National Research Service Award, clinical investigator career development awards, and Minority Investigator Administrative Supplements.

- Support researchers and other professionals who wish to spend time in crossdisciplinary sabbaticals in research related to breast cancer.

- Revise the research training guidelines to allow support for two additional years of training for postdoctoral fellows who agree to pursue research related to breast cancer.

- Provide for debt forgiveness for physicians, nurses, and others (e.g., doctoral candidates) who have completed two years of research training and who agree to devote a minimum of two years to research related to breast cancer.

- Support re-entry programs for scientists who have spent periods of time away from research. Use existing successful models to guide the development of such programs.

D. Expand the scope and breadth of biomedical and behavioral research activities related to breast cancer.

The following actions will help achieve this goal:

- Continue support for and increase the number of unsolicited meritorious investigator-initiated research grants.

- Support health services research, the development of outcome data, and studies that can determine racial/ethnic and subgroup differences.

- Increase support for research on alternative medicine and therapies.
- Extend throughout the Federal Government opportunities for support of investigator-initiated research on breast cancer. For example, continue support for the Department of Defense Breast Cancer Research Program administered by the Department of the Army under the strategy recommended by the Institute of Medicine. This program has attracted 2,400 new proposals for breast cancer research, many from investigators who were not previously involved in breast cancer research.
- Conduct studies of the relationships among nutrition, exercise, and endogenous/exogenous hormone levels. Explore the following topics: the improved measurement of hormones at the tissue level; hormone metabolism; and differences across age groups.
- Conduct investigations of environmental influences on breast cancer and on the influences of compounds that have been shown to possess estrogenic properties on the etiology and incidence of breast cancer. Enlist representatives in public and private partnerships from industry, regulatory authorities, the scientific community, and consumers in identifying strategies of research aimed at the reduction of carcinogenic exposures, and in assessing and identifying appropriate control strategies, including setting standards, labelling, controlling, and phasing out.
- Conduct clinical research on the hormonal treatment of menopausal symptoms that result from breast cancer treatment, including research on controlling the health effects of early menopause in young women being treated for breast cancer.
- Support behavioral studies on the experiences of persons living with breast cancer, particularly their strengths and coping mechanisms as well as their stresses. Support behavioral research relating to treatment effectiveness; study the role of psychological factors in survival.
- Investigate psychosocial barriers to participation in breast cancer research studies, such as professional staffs' and patients' attitudes and cultural and lifestyle factors, as well as identify strategies to overcome these barriers.
- Support studies to develop an effective model for health care organizations and delivery systems.

E. Provide adequate resources and mechanisms to speed the translation from the laboratory to the clinic of new therapeutic opportunities.

The following actions will help achieve this goal:

- Increase efforts to speed the translation of basic research findings into clinical applications wherever possible. Develop partnerships with industry employing such models as the existing National Institutes of Health Cooperative Research and Development Programs Agreements (CRADAs). Review the reasonable pricing clause in relation to CRADAs, as they impact the flow of industrial funds into clinical research and, thus, affect collaborations.
- Address the issue of liability as an impediment to industrial participation in clinical studies.
- Convene a task force on translational research related to breast cancer to identify promising new areas of basic research and actions necessary for successful translation, and to identify responsibilities for recommended actions.
- Extend the "orphan drug act" to new breast cancer therapies and technologies.

F. Conduct basic, translational, clinical, and health services research to improve breast cancer detection, treatment, and monitoring.

The following actions will help achieve this goal:

- Establish a breast cancer study section with consumer representation focused on translational research studies.
- Identify, study, and use biomarkers for detection and/or prognostic indicators for breast cancer. For example:

  -Conduct translational research and use centralized multidisciplinary decision making to rapidly define and bring promising biomarkers and prognostic indicators into clinical trials.

  -Conduct research to provide an understanding of the development of breast cancer in the majority of women who have no known risk factors. Employ these new detection biomarkers to define groups at risk for participation in new screening trials.

  -Define subsets of patients by potential for recurrence of breast cancer and select therapeutic approaches based on prognostic indicators developed from translational and clinical research.

  -Confine the use of putative biomarkers for detection and prognostic indicators to the translational and clinical research settings until their utility has been scientifically proven toapply to decisions regarding standard care.
- Target and expand both translational and clinical trials of new therapeutic opportunities including novel chemotherapeutic and hormonal agents, vaccines, gene therapy, anti- angiogenesis and antimetastatic strategies, and antigrowth factor approaches.
- Increase research on molecular genetics targeted at defining breast cancer susceptibility gene(s). For example:

  -Develop sensitive, specific, and inexpensive tests for the gene(s).

  -Conduct prospective research regarding the psychosocial, quality of life, and ethical ramifications of genetic testing as such gene(s) are identified.

  -Conduct basic and translational research using existing and planned data banks and tissue, fluid, and DNA banks from carriers and relatives of carriers to detect new biomarkers and predictors for the development of breast cancer. Extend this research to members of the general population who do not have a genetic history of breast cancer.
- Develop better methods of breast cancer detection. For example:

  -Develop a system to ensure communication between those who refer patients for detection procedures and those who provide the final diagnosis.

  -Support research to determine appropriate interventions for women at high risk of breast cancer.
- Conduct clinical research on early detection of breast cancer, including continued analysis of follow-up data from screening trials done to date. Clarify the efficacy of mammography screening for women ages 40 to 49 and women over 75 years of age.

G. Make clinical trials more widely available to women with breast cancer and women who are at risk for breast cancer.

The following actions will help achieve this goal:

- Conduct research to determine optimal methods and/or incentives (1) to facilitate widespread enrollment in clinical trials and (2) to improve compliance once enrolled. Determine ways to

incorporate safeguards to ensure the anonymity/confidentiality of women enrolled in breast cancer studies.

- Establish a mechanism of outreach to ensure that all women have access, within a reasonable geographic area, to centers conducting approved clinical research. Include outreach to areas geographically distant from research centers so that all women choosing to participate in the most promising clinical trials can do so more easily. Include the Medicare and Medicaid populations.
- Redefine quality of care to include participation in a peer-reviewed and approved clinical research trial. Develop a mechanism to offer preferential coverage for therapies and diagnostic methods offered through clinical trials or for those proven effective in peer-reviewed and approved clinical trials. Support the individual's right to refuse participation in clinical trials.
- Involve consumers, especially from populations historically underrepresented in clinical trials, in the design, planning, and evaluation of clinical investigations. Conduct research regarding the optimal means of prospective involvement of patients and their advocates in clinical trials.

H. Support research on the prevention and causes of breast cancer.

The following actions will help achieve this goal:

- Target and expand basic and clinical studies of key prevention opportunities, including prevention research (exploratory studies as well as studies based on large-scale populations), specific studies of prevention by hormonal modulation, and chemoprevention therapies.
- Increase funding for primary prevention research, including multisite and/or large-scale population-based trials.

I. Extend the scope, depth, and applications of quality of life and psychosocial research related to breast cancer.

The following actions will help achieve this goal:

- Conduct research on end-stage disease including psychosocial factors and questions of quality of life, supportive care, when to stop care, and how to deal realistically with incipient death.
- Support studies on consumer decisionmaking and the influences that affect women's use of breast health care services. Develop and implement strategies to overcome barriers to the provision and utilization of breast health care services.
- Incorporate questions related to psychosocial factors and quality of life issues prospectively in treatment and follow-up studies.
- Design behavioral research to develop, test and incorporate psychosocial interventions based on socioeconomic variables and psychosocial needs (e.g., race, culture, location, income, and stage of life).

J. Support culturally sensitive researchers and research programs related to breast cancer.

The following action will help achieve this goal:

- Expand support for studies on breast cancer in special populations (e.g., minorities, young women, older women, women in low socioeconomic status groups, and lesbians).

III. Policy

Many issues related to breast cancer require policy decisions to mandate necessary changes. Policies of government agencies are one key focus, but policy changes in all the organizations having a role in breast health are also important. The following policy actions are proposed to facilitate changes in approaches to breast cancer.

A. Implement a comprehensive plan to address the needs of individuals carrying breast cancer susceptibility gene(s).

The following actions will help achieve this goal:

- Implement safeguards and standards to prevent uncontrolled use of these new genetic testing technologies.
- Develop and enact legislation to ensure the confidentiality of the patient's genotype.
- Create a task force on safeguards and standards with participation from patients and their advocates, geneticists, physicians, consumers, as well as genetic counselors.

B. Increase participation of breast cancer advocacy groups in health policy decisionmaking.

The following actions will help achieve this goal:

- Involve advocacy groups and women with breast cancer in setting research priorities, in evaluation, and in patient education. Ensure consumer input at all levels in the development of public health programs, research studies, and clinical trials.
- Exempt the Public Health Service from Office of Management and Budget regulations regarding consumer research to allow ready use of proven social marketing techniques in breast cancer research and education. Use these techniques to determine consumer perspectives.
- Include as part of health care reform proposals mechanisms to obtain consumer feedback on health care delivery for patients with breast cancer and make this information available to consumers. Invite breast cancer advocacy organizations to monitor and report on breast cancer health care.
- Include as part of health care reform provision for: universal access to care and universal coverage (including necessary specialized care), elimination of coverage gaps and restrictions based on preexisting conditions, costs and treatments arising from participation in peer- reviewed clinical trials, and mammography screening.

C. Eliminate unnecessary confusion about breast health issues.

The following actions will help achieve this goal:

- Develop scientifically valid national guidelines about prevention, detection, diagnosis, and treatment of breast cancer for both women and health care providers.
- Develop and disseminate clear messages about what consumers, providers, and payers should do to improve breast health.

D. Make breast health management, diagnosis, treatment, and follow-up care comprehensive, compassionate, widely available, and of high quality.

The following actions will help achieve this goal:

- Initiate intragovernmental and intergovernmental agency coordination of breast cancer research in conjunction with patient and provider education and the provision of patient care. Provide for

periodic reporting to the Secretary by all relevant Federal agencies and involved non- Federal organizations in the public and private sectors.

- Work through state licensure agencies and professional national certifying and accrediting organizations to mandate competence in evaluating signs and symptoms related to breast health. Make licensure and certification contingent on such competency.
- Improve mammography systems through the Mammography Quality Standards Act (MQSA). Improve the implementation and development of feedback mechanisms linked to registries.
- Implement final standards of medical quality assurance for mammography. Finalize and implement the regulations of MQSA, which were recently issued by the Food and Drug Administration, so that all women can be guaranteed safe, high-quality mammograms.
- Provide incentives for development of educational programs for health care providers to incorporate learning objectives and curricula modules on breast health and cancer management.
- Define a range of comprehensive psychosocial services that encompass all the needs of women at risk for breast cancer as well as those women with the disease. Include in such services, where appropriate, family members and other significant persons in the woman's life.
- Expedite the review and approval of new drugs and diagnostic tests, as well as devices and technologies related to breast cancer.
- Ensure reimbursement for all costs for patients enrolled in peer-reviewed clinical trials on research related to prevention, screening, diagnosis, and treatment of breast cancer.
- Develop mechanisms of validation and quality control for all new and existing technologies to ensure against improper and substandard use.

E. Develop new and stable sources of funding for health-related research and public health activities.

The following action will help achieve this goal:

- Work cooperatively to identify new revenue sources.

F. Develop a mechanism to coordinate the implementation of action steps identified in the Proceedings of the Secretary's Conference to Establish a National Action Plan on Breast Cancer.

The following actions will help achieve this goal:

- Initiate intra- and intergovernmental agency coordination of breast cancer activities, including relevant research, education, and health care delivery activities.
- Establish a national task force that meets periodically to evaluate progress and identify new opportunities in each of the three major areas--health care delivery, research, and policy--outlined in the plan.

Appendix A

Registrants' List

January 1998

National Action Plan on Breast Cancer

1997 Summary of Accomplishments: A Report to the Steering Committee

Background

The National Action Plan on Breast Cancer (NAPBC) is a unique public/private partnership that serves as a catalyst for national efforts to coordinate actions by government and nongovernment organizations, agencies, and individuals to advance breast cancer knowledge, research, policy, and services. The NAPBC was initiated in response to the National Breast Cancer Coalition's 2.6 million-signature petition calling for a coordinated national strategy to combat breast cancer, the second leading cause of cancer deaths among American women. By encouraging new ideas and mobilizing partnerships, the NAPBC strives to "jump-start" innovative, long-term efforts that will result in rapid progress in the fight against breast cancer. The work of the NAPBC is guided by a Steering Committee and six Working Groups. Implementation of the NAPBC is coordinated by the U.S. Public Health Service's Office on Women's Health (PHS OWH) within the Department of Health and Human Services.

A Second Year of Achievement

In 1997, the NAPBC reached a new level of achievement. Building on the infrastructure and plans developed in 1996, the partnership moved decisively into the implementation stage, completing an impressive number of activities and initiatives that addressed the priorities of the Plan. Workshops in groundbreaking areas of research successfully demonstrated the effectiveness of a public/private partnership, as researchers and advocates examined the current state of the science, identified research gaps, and developed comprehensive recommendations for future research and actions. During the year, the Working Groups developed questionnaires and survey instruments, prepared publishable papers on a variety of urgent topics, and assisted with pertinent state and Federal legislation. These initiatives not only have significantly advanced knowledge in specific research areas but also have brought public awareness and the attention of high-level legislators and policymakers to important issues related to breast cancer.

The Steering Committee continued to guide the efforts of the Working Groups, refine the infrastructure of the Plan, and gain the support and collaboration of new public and private partners. In addition to reviewing Working Group budgets and activities, the Committee addressed membership issues in a continuing effort to enhance the diversity and expertise of the group. Although many important operating policies and decisions were made during the year, they are not the focus of this report. This report provides an overview of the NAPBC Working Groups' accomplishments in their second year to further national efforts to eradicate breast cancer.

The Hereditary Susceptibility Working Group

This Working Group is implementing a comprehensive plan to address the needs of individuals carrying breast cancer susceptibility genes and to advance education among consumers, health care professionals, and at-risk patient groups. During the past year, the Working Group examined a broad range of critical issues related to genetic susceptibility to breast cancer. In 1997, the Working Group:

✔ *Disseminated over 30,000 copies of the video,* Genetic Testing for Breast Cancer Risk: It's Your Choice, *to medical practitioners, cancer centers, and breast cancer organizations.* This video was designed to assist consumers in making informed choices about genetic testing. Through personal stories of breast cancer survivors, as well as experts' presentations of the pros and cons of testing, it will help women answer the complex issues of genetic testing, including how it is done, what the results mean, and what effects the results may have on them and their families. The video also can be viewed on OncoLink, the University of Pennsylvania Cancer Center Web site (the NAPBC is among the site's sponsors). In addition, the NAPBC has received several requests to broadcast the video nationally and internationally.

NAPBC Actions To Advance Policy

- *Held a press conference to discuss an article, published in* Science, *that addressed workplace discrimination based on genetic testing information. The conference produced articles in newspapers across the country and stimulated public awareness of this issue.*
- *Participated in a White House event at which President Clinton announced that legislation would be submitted to Congress to prevent discrimination in the health insurance industry on the basis of information from genetic tests.*

Jump-Starting Progress: The Hereditary Susceptibility Working Group

For many women, the exciting scientific advances to enable the identification of genes that increase the risk of developing breast cancer create a great personal dilemma: Should they be tested and possibly risk insurance and workplace discrimination? The Hereditary Susceptibility Working Group has moved rapidly on several fronts to provide information to assist women in making decisions about genetic testing, educate health professionals about genetic predisposition to cancer, identify research issues requiring immediate attention, and stimulate national policies to protect women and their families.

✔ *Developed the "Position Paper on the Ethical Marketing and Use of Genetic Testing"* to improve understanding and consensus on principles formulated to facilitate the ethical marketing and use of genetic testing.

✔ *Held a press conference* to discuss an article, published in *Science* on March 21, that addressed discrimination in the workplace based on genetic testing information. The conference produced articles in newspapers across the country and stimulated public awareness of this issue.

✔ *Convened the Workshop on Privacy and Confidentiality in Genetics Research* on September 16 and 17. The workshop was cosponsored by the National Human Genome Research Institute. At the workshop, over 100 researchers, legal and insurance experts, and patient advocates assessed protection mechanisms for confidentiality in genetics research, addressed key privacy and confidentiality issues, and developed a set of policy recommendations. Prior to the workshop, the Working Group prepared and disseminated to participants a background paper. Working Group members also worked with representatives at the U.S. Department of Health and Human Services to develop sections of the Secretary's Report on Privacy and Health Research.

Educating Consumers and Providers

- *To assist consumers in making informed choices about genetic testing, disseminated over 30,000 copies of the video,* Genetic Testing for Breast Cancer Risk: It's Your Choice, *to medical practitioners, cancer centers, and breast cancer organizations.*

- *Developed a dissemination plan for the finalized* Hereditary Susceptibility to Breast and Ovarian Cancer: An Outline of Fundamental Knowledge Needed by All Health Care Professionals, *a framework for health care providers' genetics education efforts.*

✔ *Completed* Hereditary Susceptibility to Breast and Ovarian Cancer: An Outline of Fundamental Knowledge Needed by All Health Care Professionals *and developed a dissemination plan.* The outline will serve as a framework for genetics education efforts for health care providers and establish competencies expected of them. It also will serve as a resource guide and a foundation for establishing curricula on hereditary susceptibility to cancer. One such curriculum, based on the NAPBC document, already has been developed by the American Society of Clinical Oncology.

✔ *Participated in a White House event at which President Clinton announced that legislation* would be submitted to Congress "that will ban all health plans, group and individual, from denying coverage or from raising premiums on the basis of genetic tests." The U.S. Department of Health and Human Services Secretary Donna Shalala spoke about the efforts of the NAPBC in addressing genetic discrimination and health insurance.

✔ *Served as a major information resource on the status of state legislation* on health insurance and workplace policies related to genetic information. In response to requests from the public, the media, and state and Federal policymakers, the Working Group provided current information on legislation around the country.

The Clinical Trials Accessibility Working Group

This Working Group is investigating methods to make clinical trials more widely accessible to women with breast cancer and women at risk for breast cancer. It is identifying barriers to participation in clinical trials, including barriers associated with the informed consent process,

patients' and physicians' misperceptions about clinical trials, and costs of participation. In 1997, the Working Group:

- ✔ *Developed a plan for conducting further research*—including focus groups with consumers, health professionals, and cancer patients—to obtain information for formulating a marketing communications strategy to demystify breast cancer clinical trials, promote awareness, and encourage women to learn about and enroll in such trials.

- ✔ *Conducted focus groups* on participation in clinical trials. Nine consumer and five physician telephone focus groups were completed.

- ✔ *In preparation for writing two publishable papers, analyzed and compiled information* from a critical review of the literature on barriers to and facilitators of consumer participation in clinical trials.

- ✔ *Continued consensus-building efforts* with health insurance companies, hospitals, physicians, researchers, Federal agencies sponsoring research, industry representatives, and consumer groups concerning reimbursement for breast cancer clinical trials and monitored the development of policies on informed consent issues and insurance coverage of randomized controlled trials.

Mobilizing Partnerships: The Clinical Trials Accessibility Working Group

Breast cancer clinical trials are critical to the development of new and more effective treatments and prevention strategies. These clinical trials rely on the participation of breast cancer patients and those at risk for breast cancer. Currently, however, only a small percentage of all eligible cancer patients participate in these important research trials. One of the many complex reasons women do not participate is that they may not be knowledgeable about clinical trials. The Clinical Trials Working Group is building necessary partnerships to address this problem by bringing together consumers, scientists, government representatives, health care providers, and health communications experts to make information about clinical trials more available and user-friendly and to centralize this information in a registry.

The National Biological Resource Banks Working Group

This Working Group has focused on establishing a national network of tissue banks to ensure a resource of well-characterized and well-documented biological materials for multiple areas of breast cancer research. In 1997, the Working Group:

- ✔ *Completed the analysis of results from the Needs Assessment Survey* that was sent to 20,000 researchers across the country to ascertain the quantities and types of tissue needed for breast cancer research. The results of this survey suggest that researchers want to access epidemiologically well-described materials suitable for conducting population-based studies on breast cancer; many of these materials currently are available but not to all interested researchers. Survey results were compiled in a final report that can be viewed on the NAPBC Web site.

✔ *Met with members of the College of American Pathologists* to discuss the availability of tissue for formal and informal research, and in particular how long tissues are retained. During the meeting, participants explored current practice regarding retention of tissue blocks beyond the required time limitations and incentives needed to encourage longer retention.

✔ *Developed guidelines for Institutional Review Boards (IRBs) and others, a model patient consent form, and a patient fact sheet.* After these documents were revised at a June 1997 workshop convened by the Working Group, Public Responsibility in Medicine and Research (PRIM&R), a trade group for Institutional Review Boards, presented them at its annual meeting in December. PRIM&R will disseminate the IRB guidelines to researchers, ethicists, professional societies, IRBs, and advocates. The National Cancer Institute (NCI) will coordinate and support field testing studies to validate the model informed consent form. The workshop summary and the other documents can be viewed on the NAPBC Web site.

Catalyzing Action:
The Biological Resource Banks Working Group

Research studies to understand all aspects of breast cancer biology depend on the availability of normal and breast cancer tissue. However, no national system for obtaining, storing, and registering the tissue available for use in research studies exists, and some researchers have difficulty obtaining tissue to address specific research questions. The Biological Resource Banks Working Group, in collaboration with consumers, scientists, government agencies, and professional organizations, conducted a series of initiatives to determine the availability and adequacy of existing sources of tissue, addressed ethical and legal issues involved in collecting and using biological materials, and built the foundation for a national breast cancer tissue banks network that could be maintained by collaborating partners. The Working Group has successfully accomplished its objectives and is preparing a final report on its achievements.

✔ *Assisted with the transition to NCI of the responsibility for implementing a network of tissue banks.* NCI has hired an ombudsman to serve as a central point of contact for researchers needing biological materials for breast and other cancer research studies. Information on tissue repositories can be obtained on the NCI Web site (http://cancernet.nci.gov/research.htm) or by contacting Marianna Bledsoe of the Cancer Diagnosis Program, National Cancer Institute, National Institutes of Health (301-496-7147).

The Etiology Working Group

This Working Group is focusing efforts on expanding the scope of biomedical, epidemiological, and behavioral research activities related to the etiology of breast cancer, particularly in the areas of chemicals and hormones, lifestyle factors, ionizing and non-ionizing radiation, viruses, and gene/environment interactions. In 1997, the Working Group:

✔ *Completed focus group testing on all modules of the Breast Cancer Core Questionnaire* and continued to integrate the comments into the modules. In collaboration with scientists

and consumers, the Working Group designed the core questionnaire to provide a standardized set of questions, for use by all researchers, on environmental factors linked to breast cancer.

✔ *Convened workshops* to explore several aspects of breast cancer etiology:

- Workshop on Viruses and Human Breast Cancer: Exploring the Links. The workshop recommendations will be published in the *Journal of Infectious Diseases*.
- Workshop on Physical Activity and Breast Cancer, cosponsored by the American Cancer Society and the Susan G. Komen Breast Cancer Foundation.
- Workshop on Medical Ionizing Radiation and Human Breast Cancer.
- Workshop on Electromagnetic Fields, Light-At-Night, and Human Breast Cancer.

NAPBC Actions To Advance Research

- *Developed guidelines for Institutional Review Boards and others, a model patient consent form, and a patient fact sheet.*
- *Convened workshops on a variety of research areas related to breast cancer etiology: viruses, physical activity, medical ionizing radiation, and electromagnetic fields and light-at-night.*
- *Conducted focus groups on participation in breast cancer clinical trials.*
- *Completed focus group testing of a six-module breast cancer core questionnaire designed to collect comparable data across studies.*
- *Produced a supplement to* Environmental Health Perspectives *based on presentations at the Workshop on Hormones, Hormone Metabolism, Environment, and Breast Cancer.*

Findings from each workshop are being prepared for submission to scientific journals for publication.

Understanding the Causes of Breast Cancer

Understanding the etiology, or causes, of breast cancer is critical to understanding how to prevent the disease from ever occurring and to improving treatment. Scientists know that independently and in combination, genetic, biologic, lifestyle, and environmental factors all may contribute to the initiation of breast cancer. With the assistance of consumer advocates and prominent researchers, the Etiology Working Group determines what is known about these factors and explores areas for further research.

✔ *Summarized and forwarded recommendations from the Workshop on Viruses and Human Breast Cancer* to the Director of the National Cancer Institute and officials at the Department of Defense for incorporation into their research priorities.

✔ *Published papers based on presentations* from the 1995 Workshop on Hormones, Hormone Metabolism, Environment, and Breast Cancer in a supplement to the journal, *Environmental Health Perspectives*.

- ✔ *Developed a list of resources* with information on individuals and public and private agencies that are involved in examining geographical areas in which there are elevated breast cancer rates.

The Information Action Council

The goal of this Working Group is to improve access to information about breast cancer for consumers, scientists, and practitioners via the Internet and other information technology. In 1997, the Working Group:

- ✔ *Introduced a new NAPBC Web site design* that provides easier access to the most current information and to frequently used sections of the site.

- ✔ *Expanded the NAPBC Web site,* linking with breast cancer information and resources from around the country and increasing the availability of information about NAPBC activities and efforts.

- ✔ *Augmented the information available through the NAPBC Web site by providing additional information* on breast cancer-related resources in response to online requests.

- ✔ *Developed and placed on the NAPBC Web site the "Guide to Volunteering in the Fight Against Breast Cancer,"* which directs readers to volunteer opportunities with breast cancer advocacy organizations.

- ✔ *Implemented the Bridging the Gap Initiative pilot project,* through which five community-based organizations across the nation are finding innovative ways to link informationally underserved women with breast cancer information through new technology such as the Internet and Web TV. The Working Group is providing oversight to the Bridging the Gap Initiative pilot project organizations in program activities, such as community outreach, peer advisor training, Internet access training, partnership building, and other tasks that advance the project goals.

Bridging the Gap:
Linking Women to Breast Cancer Information

Operating on the knowledge that there is a wealth of breast cancer information available over the Internet and on the principle that underserved women could benefit from this information, the Information Action Council developed the Bridging the Gap Initiative. Through a competitive procurement process in the third quarter of FY97, the Information Action Council awarded contracts to five community groups across the nation to link women to breast cancer information. The goals of the pilot project are to make the Internet available as a primary source of breast cancer information; to have women act on the health knowledge they gain through the Internet; and to expand breast cancer information networks within communities of underserved populations. Over the next two years, the IAC will observe programs in Anchorage, Alaska; Boston, Massachusetts; Bowling Green, Kentucky; Little Rock, Arkansas; and San Francisco, California, to evaluate the impact of the pilot project on the breast health practices of the diverse populations reached by this initiative.

The Consumer Involvement Working Group

This Working Group has defined several specific activities to help ensure consumer involvement at all levels in the development of national research, education, and service delivery programs related to breast cancer. The Working Group seeks to increase and institutionalize consumer participation in ongoing research, as well as in the review of research for funding, and to involve consumers in the design of service delivery and education programs. In 1997, the Working Group:

- ✔ *Developed survey instruments* for (1) consumer organizations, (2) cancer centers, and (3) pharmaceutical companies. The purpose of the surveys was to explore the nature and extent of involvement of breast cancer consumers (patients and survivors, their representatives, or those at risk) as consumer advocates in research, service delivery, public policy, and education and outreach. In collaboration with the National Alliance of Breast Cancer Organizations (NABCO) and the National Breast Cancer Coalition (NBCC), the Working Group pilot tested the consumer organization and cancer center surveys and developed strategies for survey dissemination and data collection.

- ✔ *Established a database* of cancer centers and pharmaceutical companies for use in survey mailings and management and, with assistance from NABCO and NBCC, mailed 60 industry surveys, 515 cancer center surveys, and 900 consumer group surveys.

- ✔ *Entered and analyzed data* from 186 consumer group and 193 cancer center surveys that were completed and returned. A draft report on the results was prepared as a foundation for future Working Group initiatives.

> ***Involving Consumers***
>
> *The past several years have brought many changes in how health issues are addressed. Among these changes is the increasing involvement of those affected by a disease in the development of national programs and policies. However, consumers are not yet an integral part of many health planning efforts. The Consumer Involvement Working Group is addressing this issue by gathering additional information on the nature and extent of consumer involvement in different organizations and programs to identify gaps in consumer involvement and opportunities for closing those gaps.*

NAPBC Grants Program

In 1997, the *National Action Plan on Breast Cancer Compendium of Grants* was prepared. In addition to providing contact information, the compendium summarized each grant's purpose and accomplishments.

Highlights of Upcoming Activities

Substantial progress was made in implementing NAPBC activities in 1997. Highlights of some

of the upcoming NAPBC activities for 1998 include the following:

- ✔ Three research articles generated from the Etiology Working Group's Workshop on Physical Activity and Breast Cancer will be submitted for publication.

- ✔ A genetics leadership meeting will be convened in spring/summer 1998 to educate advocate speakers on diverse genetics topics.

- ✔ Several activities will be conducted concerning multicultural aspects of breast cancer etiology. The scientific literature will be summarized, and organizations active in this area will be identified. In addition, a workshop will be convened to review and discuss the current state of knowledge about this topic and to make recommendations for future research priorities and study designs.

- ✔ Planning will begin for a workshop on hormone (estrogen) metabolizing genes, carcinogen metabolizing genes, and their relationship to environmental influences on breast cancer.

- ✔ The Breast Cancer Core Questionnaire will continue to undergo refinement. All modules, as well as a long and a short core questionnaire, will be completed. The questionnaire and an accompanying interviewer's manual will be available on the Web site in late 1998.

- ✔ Links to Internet resources concerning areas with elevated breast cancer rates will be placed on the NAPBC Web site.

- ✔ An initiative to design and produce a toolkit to encourage communities to build Web sites about local breast cancer resources will be explored.

- ✔ Fact sheets on individual accomplishments and a final report of the National Biological Resource Banks Working Group will be prepared.

- ✔ In a continuation of efforts to identify barriers to participation in clinical trials, three focus groups with people diagnosed with cancer are planned for early January 1998.

- ✔ Two papers on participation in clinical trials will be submitted for publication in spring 1998—one on healthcare provider-based barriers to patient participation and the other on patient barriers to participation and strategies to overcome these barriers.

- ✔ The Hereditary Susceptibility Working Group will continue to facilitate the advancement of policies to prevent workplace discrimination based on genetic information.

WIN Against Breast Cancer

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from Bobbie, fyi.

Fax Transmission Cover Sheet

Date: 10-7-98 Ms. Bobbie Greenand

To: Ms. Neera Tanden, Office of the First Lady

Fax #: (202) 456-6244

From: Elizabeth Mullen, CEO, WIN Against Breast Cancer

Message

Subject: Wilson vote of AB 2592 - CA Breast Cancer Treatment Fund for Indigent / Uninsured

Please find, as transmitted full text of op-ed in today's LA Times.

(This fax may precede the Exec Summary of same I am sending you.)

This fax should contain 3 page (s), including the cover sheet.
If you do not receive the complete transmission, please call
(626) 332-2255

Where Is the Governor's Compassion?

■ Breast cancer: Wilson kills a bill that would have aided low-income women with no other medical coverage.

By RUTH ROSEN

Imagine that your mother, wife or sister goes for a mammogram and discovers, much to her shock, that she has early breast cancer. Your insurance company pays for the mammogram but refuses to pay for any treatment—not surgery, chemotherapy or radiation. Not plausible? Well, Gov. Pete Wilson just inaugurated Breast Cancer Awareness Month by vetoing a bill that would have paid for the treatment of poor women diagnosed with the disease.

For years, health departments have been cajoling poor women to come in for mammograms. The Breast Cancer Early Detection Program, which offered early screening detection for these women, proved quite successful. And so, the women came. The problem, however, was that many providers in the program did not have the funds to treat those women who ended up having the disease. Not surprisingly, the women, already terrified by the diagnosis, were aghast.

These women are among the 24% of all Californians, including children, who have no health coverage, including no Medi-Cal or Medicaid. They are largely those who work at minimum wage or slightly above or are between jobs. Assembly Bill 2592 was supposed to fix this deplorable situation. By using general state funds, the bill would have provided treatment for these low-income women whose screening resulted in a diagnosis of breast cancer. But our good governor, in a typical display of "compassion," decided that it was in the best interests of the state to veto the bill. Why? Apparently, we don't want such women to feel too entitled. After all, we're already paying for them to be screened. Why should we be required to pay for their treatment too? In his own words, Wilson announced, "I am returning Assembly Bill No. 2592 without my signature. This bill would establish the Breast Cancer Treatment Program within the Department of Health Services to provide breast cancer treatment services to uninsured and underinsured women with income at or below 200% [twice] the federal poverty level.

"This bill would create General Fund pressure to keep pace with expanding treatment demands."

In other words, we'll screen women, but not treat them. In a state now blessed with a surplus, does it make sense to deprive poor women of treatment for breast cancer? Of course not. It reeks of moral bankruptcy and indecency, a sign of Wilson's disregard for the welfare of poor women and a statement of their dispensability. Shades of Jonathan Swift's "Modest Proposal": Perhaps if we allow poor women to die, we won't have to worry about welfare anymore.

In California, 21,485 women died from breast cancer between 1990 and 1994. In 1998, an estimated 4,300 women will lose their lives to breast cancer and 17,600 new cases will be diagnosed. Between March 1997 and April 1998, the Breast Cancer Early Detection Program provided breast cancer screening and diagnostic services to 101,407 low-income women aged 40 and older. Approximately 1,300 low-income women will discover, through early screening during the next 20 months, that they have breast cancer, but no treatment will be provided.

To detect early breast cancer without providing treatment is like diagnosing serious heart disease and refusing to provide either drugs or surgery. It is a preposterous idea. I am alive because I am a privileged woman whose medical insurance paid for early detection, surgery, chemotherapy and radiation. So is U.S. Supreme Court Justice Sandra Day O'Connor, former state Chief Justice Rose Bird, Nancy Reagan, Betty Ford, actress Jill Eikenberry, Gloria Steinem, 18 friends and millions of other women. But every woman, whatever her income or background, should have access to the same screening and treatment that we received.

Wilson's veto is a disgrace. It reveals a misogynistic indifference to poor women that borders on the pathological. What an incredible way to remind the public that October is Breast Cancer Awareness month.

Ruth Rosen, currently a visiting professor at the Goldman School of Public Policy at UC Berkeley, regularly writes on politics and culture.

L.A. Times, 10/7/98

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AROUND CALIFORNIA

OPINIONMAKERS

#11 BREAST CANCER: Op-Ed Calls Wilson A 'Misogynist' For Vetoing Treatment Bill

OPINIONMAKERS

#11 BREAST CANCER: OP-ED CALLS WILSON A 'MISOGYNIST' FOR VETOING TREATMENT BILL

Writing in today's Los Angeles Times, UC-Berkeley professor Ruth Rosen blasts Gov. Pete Wilson's veto of a bill (AB 2592)"that would have paid for the treatment of poor women diagnosed" with breast cancer, a veto that came despite existing state subsidies for mammograms. "In other words," Rosen writes, "we'll screen women, but not treat them. In a state now blessed with a surplus, does it make sense to deprive poor women of treatment for breast cancer? Of course not. It reeks of moral bankruptcy and indecency. ... [If we allow poor women to die, we won't have to worry about welfare anymore." She goes on to say that the veto "reveals a misogynistic indifference to poor women that borders on the pathological" and concludes that Wilson's action is "an incredible way to remind the public that October is Breast Cancer Awareness month" (10/7).

WHAT IT WOULD HAVE DONE

Introduced by Assemblyman Howard Wayne (D-San Diego), AB 2592 would have offered breast cancer treatment services to uninsured and underinsured women with incomes at or below 200% percent of the federal poverty level. According to the California Assembly's digest, the program would have been administered by the Department of Health Services, though the bill required the department to contract the program's operations out to a qualified organization.

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FROM : WIN Against Breast Cancer PHONE NO. : 818 332 2585 Oct. 07 1998 12:02PM P1 TOTAL P.05

UC Berkeley - Goldman School of Policy
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Where Is the Governor's Compassion?

■ Breast cancer: Wilson kills a bill that would have aided low-income women with no other medical coverage.

By RUTH ROSEN

Imagine that your mother, wife or sister goes for a mammogram and discovers, much to her shock, that she has early breast cancer. Your insurance company pays for the mammogram but refuses to pay for any treatment—not surgery, chemotherapy or radiation. Not plausible? Well, Gov. Pete Wilson just inaugurated Breast Cancer Awareness Month by vetoing a bill that would have paid for the treatment of poor women diagnosed with the disease.

For years, health departments have been cajoling poor women to come in for mammograms. The Breast Cancer Early Detection Program, which offered early screening detection for these women, proved quite successful. And so, the women came. The problem, however, was that many providers in the program did not have the funds to treat those women who ended up having the disease. Not surprisingly, the women, already terrified by the diagnosis, were aghast.

These women are among the 24% of all Californians, including children, who have no health coverage, including no Medi-Cal or Medicaid. They are largely those who work at minimum wage or slightly above or are between jobs. Assembly Bill 2592 was supposed to fix this deplorable situation. By using general state funds, the bill would have provided treatment for these low-income women whose screening resulted in a diagnosis of breast cancer. But our good governor, in a typical display of "compassion," decided that it was in the best interests of the state to veto the bill. Why? Apparently, we don't want such women to feel too entitled. After all, we're already paying for them to be screened. Why should we be required to pay for their treatment too? In his own words, Wilson announced, "I am returning Assembly Bill No. 2592 without my signature. This bill would establish the Breast Cancer Treatment Program within the Department of Health Services to provide breast cancer treatment service to uninsured and underinsured women with income at or below 200% [twice] the federal poverty level. . . . This bill would create General Fund pressure to keep pace with expanding treatment demands."

In other words, we'll screen women, but not treat them. In a state now blessed with a surplus, does it make sense to deprive poor women of treatment for breast cancer? Of course not. It reeks of moral bankruptcy and indecency, a sign of Wilson's disregard for the welfare of poor women and a statement of their dispensability. Shades of Jonathan Swift's "Modest Proposal": Perhaps if we allow poor women to die, we won't have to worry about welfare anymore.

In California, 21,485 women died from breast cancer between 1990 and 1994. In 1998, an estimated 4,300 women will l their lives to breast cancer and 17,(new cases will be diagnosed. Betwe March 1997 and April 1998, the Bre Cancer Early Detection Program p vided breast cancer screening and di nostic services to 101,407 low-inco women aged 40 and older. Approximat 1,300 low-income women will discov through early screening during the n 20 months, that they have breast canc but no treatment will be provided.

To detect early breast cancer with providing treatment is like diagnosing rious heart disease and refusing to p vide either drugs or surgery. It is a p posterous idea. I am alive because I ar privileged woman whose medical ins ance paid for early detection, surge chemotherapy and radiation. So is U Supreme Court Justice Sandra D O'Connor, former state Chief Just Rose Bird, Nancy Reagan, Betty Fo actress Jill Eikenberry, Gloria Steine 18 friends and millions of other wom But every woman, whatever her inco or background, should have access to same screening and treatment that we ceived.

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Ruth Rosen, currently a visiting p fessor at the Goldman School of Pul Policy at UC Berkeley, regularly wri on politics and culture.

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To detect early breast cancer without providing treatment is like diagnosing serious heart disease and refusing to provide either drugs or surgery. It is a preposterous idea. I am alive because I am a privileged woman whose medical insurance paid for early detection, surgery, chemotherapy and radiation. So is U.S. Supreme Court Justice Sandra Day O'Connor, former state Chief Justice Rose Bird, Nancy Reagan, Betty Ford actress Jill Eikenberry, Gloria Steinem, 18 friends and millions of other women. But every woman, whatever her income or background should have access to the same screening and treatment that we received.

Wilson's veto is a disgrace. It reveals a misogynistic indifference to poor women that borders on the pathological. What an incredible way to remind the public that October is Breast Cancer Awareness month.

RUTH ROSEN
LA TIMES 10/7/98
Where is the Governor's Compassion?

- Breast cancer: Wilson kills a bill that would have aided low-income women with no other medical coverage.

AMERICAN CANCER SOCIETY®

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AMERICAN CANCER SOCIETY®

October 2, 1998

Jennifer Klein
Office of the First Lady
The White House
Washington, DC

Dear Ms. Klein:

In follow to our meeting yesterday, I am forwarding the project description that I promised. After our meeting, we discussed the possibility of scheduling a breakfast meeting in Washington, D.C. to announce the breast cancer advocacy leadership initiative that the American Cancer Society will cosponsor with the National Association for the Advancement of Colored People. October 30 may be the date that will work best for the planning of this event.

We would like to remain flexible for as long as possible in order to accommodate the First Lady's schedule. However, our planning will be much easier when we have a firm date and time. Please contact Susan Polan at (202) 661-5716 as soon as you have information about Mrs. Clinton's schedule and the possibility of her participation.

Thank you for meeting with us yesterday. Your interest in the work of the Society is greatly appreciated.

Yours truly,

Charles A. Jackson
Director of Collaborative Programs
and Advocacy for Special Populations

Enclosure

cc: Susan Polan, PhD

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LEADERSHIP DEVELOPMENT FOR BREAST CANCER ADVOCACY

Project Description

Introduction

The American Cancer Society and the National Association of the Advancement of Colored People will cosponsor a leadership development conference to recruit and prepare a core group of talented and highly motivated women of color to become leading advocates for breast and cervical cancer control at the national and state levels.

This two-day conference will help to prepare a cadre of new leadership who will advance the interests of African American women as public policies related to breast and cervical cancer are being debated and formed. Our hope is that these women will eventually assume leadership positions within the breast and cervical cancer advocacy movement and recruit other African American women over the coming years so that the movement may become more representative of all women who are affected by these diseases.

Background

In 1998, approximately 178,700 women will be diagnosed with breast cancer. Though breast cancer incidence is on the decline overall, incidence of breast cancer among African American women increased between 1990 and 1995. African American women are slight less likely to be diagnosed with breast cancer than white American women, but they are more likely to die from the disease. In the period from 1990 to 1995, the breast cancer mortality rate for African American women was 21 percent higher than the rate for white American women (31.5 deaths versus 26.0 deaths per 100,000 women, respectively). About 43,500 women in the United States are estimated to die from breast cancer in 1998, making it the second largest cause of cancer death.

An estimated 13,700 women will be diagnosed with cervical cancer and 4,900 women will die from the disease in 1998. Almost all deaths from cervical cancer can be prevented by early detection and prompt treatment. The cervical cancer mortality rate for African-American women during the period from 1990 to 1995 was more than two times greater than the rate for white women. White American women are more likely than African Americans women to have their cervical cancers diagnosed when the cancer is in an early, localized stage. Only

forty percent (40%) of cervical cancers among African-American women are diagnosed at the local stage.

Numerous studies have shown that early detection increases survival rates and treatment options. Unfortunately, minority women -- as well as women of low socioeconomic status, the elderly, the uninsured, and women who live in rural areas -- experience barriers to access to cancer screening and treatment. Common barriers include costs, transportation problems, and lack of child care.

As government funds are being allocated, African Americans must be involved in the policy making process as advocates to communicate their communities' interests in federally-funded cancer research and programs for the early detection of cancer. If we as a nation apply equitably all that we now know about cancer prevention, control and treatment, the lives of many women can be saved, extended, and improved.

Conference Objectives

The goal of the breast cancer advocacy leadership conference will be to facilitate aggressive advocacy on behalf of African Americans in federal and state public policy arenas, as well as in community-level planning, program implementation, and grassroots mobilization for cancer control in underserved populations. Specifically the conference will:

- Provide training in leadership, community organizing, advocacy, and organizational development;
- Facilitate discussion about the most effective approaches to breast and cervical cancer control in the African American community and define public policy goals aimed at reducing breast and cervical cancer incidence and mortality among African American women;
- Familiarize participants with the nature of financial and organizational resources for breast and cervical cancer control at the local, state, and federal levels;
- Help participants identify a broad range of traditional and nontraditional partners for collaboration in cancer control planning, programming, and advocacy at the federal, state, and local levels;

Participants

Participation will be limited to a select group of no more than fifty women who have previous advocacy experience, a desire to learn from others and share knowledge and lessons learned from past advocacy experience, and the potential to assume a leadership position in the breast cancer advocacy movement. Participants will be selected in order to maximize diversity of backgrounds and skills. By restricting participation to this select group, we hope to foster and environment conducive to open, honest dialogue, learning, and team-building.

Outline for Breast Cancer Report

Pre-Report
Letter from Secretary Shalala and possibly other Cabinet Secretaries to place at the front of the report. (This should include a brief synopsis of the highlights, which should refer to the increases in funding under the Clinton Administration.)

Report

1. Profile of Breast Cancer Statistics: Relatively brief discussion of where we are on breast cancer -- mortality rates, incidence rates, etc.

2. Science: A chapter, with a more objective tone, that describes in some detail the advances that have been made in breast cancer over the last several years, in terms of both treatment and prevention. Throughout this chapter, there should be connections (albeit somewhat subtle) between these advances and the Administration's actions (e.g. FDA approval of breast cancer drugs, new investments in research).

3. The Changing Nature of Breast Cancer (or some other catchall). This chapter should in some way address:
-- quality of life issues
-- outreach
-- coordination of efforts
-- minority women
-- older women
Again, we should also highlight all the Administration had done on these issues, and this may be even more like an accomplishments document than the rest of the report. For example, it would be good to highlight in some way how we have made so much progress on the National Action Plan. At the end of this section, there should be some discussion about the attempts to find a cure.

4. Challenges Ahead: This chapter should discuss how with all our progress, we have now have new challenges in front of us. These challenges should represent some kind of consensus between the federal agencies and activists.

Sarah A. Bianchi 09/29/98 09:14:13 AM

Record Type: Record

To: Jennifer L. Klein/OPD/EOP
cc: Christopher C. Jennings/OPD/EOP
bcc:
Subject: Re: Breast Cancer

The idea of this is that we are asking all scientists/experts to come up with out of the box approaches to developing new innovative ways to fight, detect, etc. cancer. I don't know if it has to do explicitly with breast cancer but I am sure there is (or could be) a link. We did include it in press paper this weekend, but neither the President or the VP mentioned it, so maybe we could somehow reconfigure it , although they won't be ready to announce the grants until January. (see description below.) The other thing we included in announcement, but did not discuss is the survivorship grants. Maybe there is more there. It's kind of an interesting issue -- understanding lifelong issues for survivors. Also,
What is the status of mammography quality standards act reauthorization? Is timing wrong?
What happened to the idea of directing HHS to do report on status of breast cancer action plan etc.?
Have you talked with NIH at all about their campaigns?? Any way to make that sound big? I don't kow if that's helpful. Happy to help in anyway I can..

sb

> **Issued nationwide challenge for new technological approaches to fight cancer.** Winning the war against cancer requires innovative approaches to prevent, detect, treat, and one day cure this disease. Today, the Director of NCI announced a $48 million competitive grant program for researchers to apply new technologies -- from areas such as computer science, engineering, military defense, and astronomy -- to prevent, detect, and treat cancer.
>
> **Unveiled groundbreaking research grants to examine how to prevent cancer recurrence, understand the lifelong impact of cancer treatment, and to improve the quality of life for cancer survivors.** The Vice President announced that the NCI is releasing $15 million in new cancer survivorship grants to fund top-of-the-line research to examine the impact of this disease on patients and their families. Specifically, researchers will examine the long-term effects of cancer treatments and the most effective ways to prevent recurrence of cancer and to improve the quality of life for cancer survivors and their families.

Jennifer L. Klein

Jennifer L. Klein
09/28/98 06:06:25 PM

Invite

Yes

Governor's Mansion
Frankfort, Kentucky 40601

FAX Message

Number of Total Pages: 3

To. Melanne Verveer
Executive Assistant to First Lady Hillary Clinton
Fax Number: (202) 456-6244

From: Kay Harrod
Executive Assistant to Kentucky First Lady Judi Patton

Date: September 3, 1998

Re: October Breast Cancer Awareness Month

It was brought to our attention Monday that Mrs. Clinton may be participating in some activities during October for Breast Cancer Awareness Month. We are faxing to you (and forwarding the original copy), a letter to Mrs. Clinton from Mrs. Patton outlining several activities for which we would be delighted to host Mrs. Clinton.

If you have any questions or problems with the delivery of this fax, please don't hesitate to call me: (502) 564-8004. Thanks.

Governor's Mansion
Frankfort, Kentucky 40601

September 2, 1999

Mrs. Hillary Rodham Clinton
First Lady
White House
1600 Pennsylvania Avenue NW
Washington, D.C. 20500

Dear Hillary:

I have just returned from Puerto Rico and the Southern Governors' Meeting and have learned that you are interested in activities to attend during October for Breast Cancer Awareness Month. I have three very special events of which I would like to make you aware for your possible attendance and/or involvement.

On October 2, 1998 at noon, Paul and I will convene, in Frankfort, Kentucky's first-ever Breast Cancer Task Force. This group of Kentucky physicians, radiologists, nurses, public health officials, researchers, insurance company representatives, lawmakers, survivors and breast cancer activists will meet for one year to assess the state of breast cancer in the Commonwealth. Our ultimate goal is that this group will provide for Paul the necessary findings to formulate a plan to present to our legislature in 2000 to address the needs of all of Kentucky's women with regard to funding, access to mammography services, care, treatment and follow-up support. We would be delighted for you to provide the Challenge for our first meeting.

The Task Force is drawing considerable statewide media interest and I am sure that our first meeting will be highly publicized. We have spent since February, when Paul drafted the executive order, looking for members who are dealing directly with breast cancer issues and who will commit to this year-long project. We feel that this 60-member task force will tackle this project with great enthusiasm. An epidemiologist will present the data from a researcher we have had working since June and we will be using Dr. Tom Kean, a recognized facilitator from the University of Colorado. Dr. Gilbert Friedell of the Kentucky Cancer Program and nationally recognized for his years of work with cancer will serve as our executive director.

Another opportunity is October 5. It is a statewide television show that we will do in conjunction with Kentucky Educational Television, the Markey Cancer Center and the University of Kentucky Department of Agriculture. It is called *Stories of Hope*. This program will feature both live call-ins and taped segments. It will be hosted by Dr. Carla Craycraft of U.K. (a breast cancer survivor), Dr. Ben Roach of the Markey Cancer Center foundation and University of Kentucky football coach Hal Mumme and his wife June, who is battling breast cancer. June recently published a book about her life with Hal and how they are dealing with her diagnosis. We would be delighted to arrange a live phone call-in feed to the broadcast from you at the White House or perhaps you might wish to do a video taped message.

The third event is our annual state meeting of the Kentucky Breast Cancer Coalition for which I serve as honorary chair. This meeting will be held on October 7, here in Frankfort. I believe a letter concerning this event has already been sent to you by Linda Piker, chair of the KBCC. Paul and I will host this group at the Mansion at the conclusion of their day-long program, where we will do the state proclamation for Breast Cancer Awareness month, provide information on the work of the Governor's Breast Cancer Task Force and announce our participation in the Wall of Hope begun by Marilyn Axelrod of California. I'm sure you have been in contact with Gayle Wilson of California about this project. As part of my Mother's Day focus on breast cancer, it is our hope to host more than 500 survivors in Frankfort in May to be photographed for the wall. Your presence at the October meeting would be a tremendous boost to the 200 or more survivors who will attend.

I will be most happy to provide additional information to your staff on any of these three programs. Paul and I will be delighted to serve as your hosts should you choose to come to Kentucky. If you require further information, please call my executive assistant Kay Harrod at (502) 564-8004.

As always, you have my very best wishes.

Sincerely,

Judi Patton

MULTI-CITY MAMMOGRAPHY PROJECT

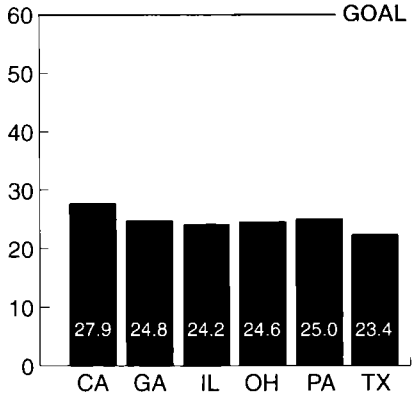
Aim

Create locally initiated and locally owned breast cancer awareness programs.

Background

The Multi-City Mammography Project is part of HCFA's National Mammography 2000 Campaign. The goal of the National Mammography 2000 Campaign is to increase the number of Medicare beneficiaries who receive a screening mammogram to 60 percent. In cooperation with this goal, the Multi-City Mammography Project will target African-American and Hispanic Medicare beneficiaries in six major metropolitan areas where screening mammography rates range from 24.2 percent to 27.9 percent for all women age 65 and older. Rates for African-American and Hispanic women are even lower.

Beginning January 1, 1998, Medicare will cover screening mammograms every year for women age 40 and older with no deductible. Previously, Medicare would cover mammograms once every 24 months. The Multi-City Mammography Project will help to disseminate this information to its target audience and help to improve utilization of the new benefit.



Target Cities and Audiences

The Multi-City Mammography Project selected the following target audiences in these six cities:

Atlanta	**African American**
Chicago	**African American and Hispanic**
Cleveland	**African American**
Los Angeles	**African American and Hispanic**
Philadelphia	**African American**
San Antonio	**Hispanic**

Methods

As the first step, HCFA needed to better understand the knowledge, attitudes, and beliefs of African-American and Hispanic Medicare beneficiaries. In addition, there was a need to understand the knowledge, attitudes, beliefs, and referral patterns of health care providers with regard to screening mammography in

Methods (cont.)

women age 65 and older. This was accomplished by conducting a market analysis. Since environmental influences can have a bearing on health beliefs and behaviors, it was necessary to conduct the market analysis in each city separately.

Another aspect of the market analysis was to determine what other organizations, agencies, and entities were concerned with on the health issues of African-American and Hispanic populations. These organizations were to become potential partners in the development and implementation of the Multi-City Mammography Project's interventions.

Conferences were held in each of the six cities in order to include as many of the potential local partners as possible. Each invitee was provided with a copy of the market analysis in preparation for the conference. Conference attendees were asked to discuss a variety of issues regarding the use of screening mammography among African-American and Hispanic women, as well as barriers to receiving the test. The results of the conferences were the forming of initial partnerships and the planning for interventions to increase awareness among beneficiaries and health care providers about the benefits of screening mammograms.

Partners

The primary partners in the Multi-City Mammography Project are the HCFA Central Office, HCFA Regional Offices, and Peer Review Organizations (PRO) in six states. Local partners will consist of the local chapters of the American Cancer Society, State and City Health Departments, State Agencies on Aging, local cancer control advocacy groups, and local physician organizations. Additional partners will be added as plans for interventions are completed.

Next Steps

By January 15, 1998, each PRO will submit a plan of action to address the specific identified needs in each of the six cities. All plans will be jointly written with the assistance of the local partners. Later in 1998, locally developed interventions will be initiated and measured.

For Additional Information

Contact: Jim Coan
Health Insurance Specialist
Education and Health Promotion Group
410-786-9168 or JCoan@HCFA.gov

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
002. list	Revised [Personally Identifiable Information] [partial] (1 page)	09/10/1998	b(6)

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First Lady's Office
Jennifer Klein
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FOLDER TITLE:
Breast Cancer/Mammography 1998 [2]

2014-0536-S
kc1551

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P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
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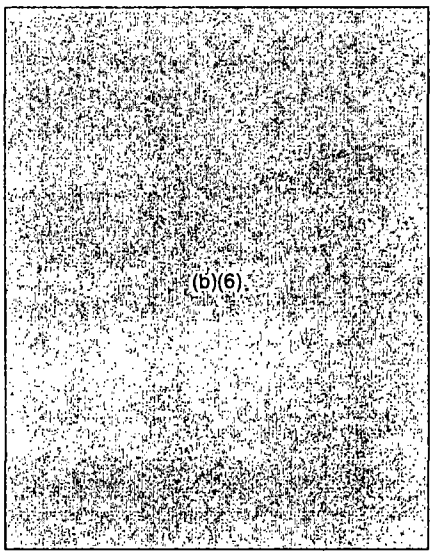
b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

[002]

Revised

HHS	Elizabeth Summy
OWH	Anna Kinderman
OWH	Susan Wood
FDA	Audrey Sheppard
NCI	Paul Van Nevel
NCI	Nelvis Castro
NCI	Dr. Otis Brawley
HCFA	James F. Coan
HCFA	Sandra K. Kappert



MEMORANDUM

April 16, 1998

TO: Chris and Jen

FR: Sarah B.

RE: Expanding Medicaid to Women in CDC Breast Cancer Screening Program

The National Breast Cancer Coalition has called to ask for the Administration to support legislation that would extend Medicaid coverage to women who have been diagnosed as having breast or cervical cancer by having been screened by the National Breast and Cervical Cancer Early Detection Program run by the CDC. The bill is scheduled to be introduced next Wednesday by Senators D'Amato, Snowe, Miluski, and Moynihan as well as Representative Kennelly and possibly others on the House side.

The CDC program, started in 1990, will receive $140 million in 1997 to screen low-income women (up to 250 percent of poverty) for breast and cervical cancer. So far it has screened over 500,000 women, found over 32,218 abnormal mammograms, and diagnosed 2,918 cases of breast cancer. Of those who have been diagnosed, 2,327 were under the age of 65 and therefore ineligible for Medicare. It has also provided 612,008 Pap tests and 24,434 were abnormal and 19,166 cases of cervical cancer were diagnosed.

How Women Diagnosed With Cancer Currently Receive Treatment

While there are currently no funds available in this program to treat women diagnosed with cancer, most of the women who have been diagnosed up to now have received treatment. In fact, CDC's data shows that 96 percent of positively diagnosed women have received treatment, usually in a timely manner. States have cobbled together various ways to extend treatment for these women. Because of the popularity of the CDC program, there have been private donations from organizations such as the Susan B. Komen Foundation as well as local efforts to raise money for these programs, such as Sororities and local businesses holding fundraisers, or providers agreeing to treat these women.

However, there are adverse consequences from this piecemeal approach. First, the states and the program itself are spending an inordinate amount of resources finding treatment for women with cancer. In fact, many doubt that as the program grows it will not be able to find a way to identify funds for all of women who need treatment. Moreover, a recent MMWR report released by CDC noted that some providers and many women have been reluctant to participate in the program because they fear they will not be able to pay for treatment if cancer is identified.

Legislative Proposal

This legislation provides Medicaid coverage for women who are diagnosed with breast or cervical cancer through the NBCCP program. This would be a state option and would allow the state to make treatment available during a period of presumptive eligibility. As you may recall, the National Breast Cancer Coalition did ask us to support this late in the balanced budget process. However, their request came during the final days of negotiations, and we were able to say no on the basis that we were not supporting any new provisions at that time because it would undermine the deal. The proposal has been scored by CBO as costing $100 million over five years.

Pros/Cons

Extending Medicaid coverage to these women would certainly ensure a more stable funding source to ensure that the women who enter this program receive treatment. CDC believes that it would free up many resources that are currently spent trying to find treatment for the women identified. There is also some precedence for this. Apparently, (I am still checking out) in 1993, we enacted the Tuberculuous Optional Benefit Program, which allowed states the option of expanding Medicaid to people with TB.

However, you are obviously well aware of the implications for the Medicaid program and the extent to which this would create a precedent to open up Medicaid disease by disease. While most of CDC's programs focus on education and outreach rather than screening for chronic diseases that sometimes require long term follow up care, there are other programs, such as cardiovascular and diabetes treatment programs (although much smaller than the breast cancer screening program), that could benefit from a link to the Medicaid program. There are also other Federal programs, such as Ryan White, that expend a great deal of resources treating people with HIV/AIDS. While Ryan White, unlike the CDC program, does not have any legislative barriers to providing treatment, clearly it could help more people if they could guarantee Medicaid as the payor of care. Moreover, there are many others diseases that do not have specific Federal public health programs associated with them but still would benefit from extending Medicaid. The current controversy over whether to extend Medicaid to people with HIV at an earlier stage in their disease is currently the most visible example.

There is also the question of whether it is good public policy to extend Medicaid only to women who have participated in a particular Federal program. While the CDC program does have a presence in all fifty states, it is certainly not available to all women who fit the income criteria. This policy would extend Medicaid to some women with breast cancer who are in a certain income bracket but not others who are at the same or perhaps at an even lower income bracket. The NBCC and CDC have explored (although I believe only briefly) other ways of assuring treatment for women in this program. One idea is to expand the funding for the program to assure treatment services. The program is currently not equipped to provide breast cancer treatment and while they could develop links to local providers, CDC is not currently equipped to be a payor for these women. That being said, there are probably creative ways that could be explored to create a more stable source of funding. The NBCC is interested in the Medicaid option in part because it is a stable source of funding that does not fall under discretionary caps.

The NBCC is coming into town in early May and the First Lady is scheduled to do something on their behalf while they are in town. How do we want to respond both to their request for support as they unveil the legislation next week as well as when (and if) the First Lady chooses to do something when they are in town. You should note that this issue is one of the three highest priorities for the NBCC. The first two are eliminating genetic discrimination and expanding coverage of cancer clinical trials. We have supported legislation and been highly visible on both of these issues and, as you well know, went out of our way to develop a cancer clinical trials proposal that was acceptable to the group. Please advise how you would like to proceed. S

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Pamphlet, "Take a Step Toward Good Health," = 2 pages

[redacted]

For Information on:

Medicare coverage for mammograms, call the Medicare Hotline at 1-800-638-6833 or call your local Medicare carrier listed in your "Your Medicare Handbook."

Breast cancer and mammograms, call the National Cancer Institute's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237). People with TTY equipment, dial 1-800-332-8615.

Developed by:

Food Marketing Institute

National Cancer Institute

National Urban League

US Department of Health and Human Services

Food Drug Administration

Take a Step Toward Good Health

[redacted]

[redacted]

Barbara D. Woolley
07/08/98 08:07:14 PM

Record Type: Record

To: Neera Tanden/WHO/EOP, Jennifer L. Klein/OPD/EOP, Brenda B. Costello/WHO/EOP

cc:
Subject: Medicare Mammography Initiative - Drop By - Briefing

July 8, 1998

PHOTO OP WITH CORPORATE PARTNERS OF THE MEDICARE MAMMOGRAPHY INITIATIVE

DATE: Thursday, July 9, 1998
TIME: 11:00 AM
ROOM: Diplomatic Room
FROM: Minyon Moore
Barbara Woolley

I. PURPOSE

To thank the corporate partners for their continued support of efforts to highlight the Medicare Mammography Initiative, which provides prevention benefits in order to deter breast cancer.

II. BACKGROUND

You will participate in a photo op with 18 representatives of the national sponsors and corporate partners of the Medicare Mammography Initiative. This event continues your support for this initiative, which you have been involved with since 1993. Last year, you and the President highlighted the efforts of the Medicare Mammography Initiative and its partners at a Saturday Radio Address during Breast Cancer Awareness Month in October of 1997. In 1996, you participated in a panel with breast cancer survivors in Room 450 of the OEOB to highlight the Initiative. On Mothers Day, 1994, you held an event in the East Room with senior women and advocates to highlight your efforts from town hall meetings you had held earlier on this issue.

The corporations represent a list of those most active in worksite mammography initiatives and local or national breast cancer awareness campaigns. Their efforts vary in focus and implementation, yet all are exemplary in their commitment to increasing awareness of and access to mammography. Most of the corporations encourage women in their workplace to ensure they have regular mammograms (e.g. health plan coverage, promoting mammography to empolyees, paycheck stuffers etc.) At the next level, some corporations go beyond the limitation of their health plan coverage by paying for the entire cost of mammography, allowing time off for a mammogram, arranging for worksite mobile vans, or extending services to dependents and retirees. A small group of corporations, which are the most exemplary on women's health, are those whose commitment extend beyond the worksite to include support for community outreach and/or national mammography awareness.

III. PARTICIPANTS

* See list attached.

IV. SEQUENCE OF EVENTS

* YOU enter room and take individual photos.
* YOU make brief remarks and depart.

V. PRESS PLAN

Closed press.

VI. REMARKS

Talking points attached.

VII. ATTACHMENTS

List of Participants.
Corporate Partners Commitments, 1997.

TALKING POINTS

* Thank you for your continued support to this Initiative.

* I'd like to acknowledge the national sponsors -- Avon (who could not be here today), Eli Lilly & Company, Eastman Kodak Company, and Zenecca who help make the PSA's possible.

* I'd also like to thank the corporate sponsors who help get the message out to either your employees, customers and worksite programs.

* As I've traveled the country, I've come across so many women who have been unaware of the resources available to them. As you all know, early detection is critical to saving lives, and that's why the public private partnership that we have engaged in is so important. Your efforts to inform women of the urgency of mammogram tests and how they are increasingly available is doing immeasurable good for the health of women in this country.

* Your continued commitment and partnership to this effort is critical. The need for your help is even greater today than yesterday.

National Mammography Campaign
National and Corporate Commitments

National Commitments

* **Avon**

  Involvement of 425,000 sales representatives in woman-to-woman reinforcement of the importance to mammography: distribution of 15 million consumer flyers.

  Sales brochure message about mammography importance: 60 million print impressions.

  Continuation of funding for 250 community organizations that link medically underserved women to Medicare and other mammography services.

* **Eli Lilly**

  The Breast Education and Mammography Screening Center at its Indianapolis-based corporate center is Indiana's only on-site mammography center dedicated to employees, retirees, and spouses over the age of 40. It offers its services and educational material free of charge.

  The Lilly subsidiary PCS Health Systems, Inc. is using its on-line information system to communicate with nearly every U.S. pharmacy to encourage women age 65 and over to get their Medicare-covered mammograms every two years.

* **Zenecca, Inc.**

  Supports Initiative through the National Breast Cancer Awareness Month campaign of which National Mammography Day, October 17, is a key component.

  One of the first companies to provide on-site screening to its employees and has developed a comprehensive guide to help any employer institute mammography programs for their employees.

* **Eastman Kodak Company**

  Distributes information with Supplement piece in September/October Employee Newsletter that reaches 50,000 retirees.

  Distributes 2,000 posters to communities with Eastman Kodak plants as well as making mammograms available at the worksite for Kodak employees.

  Thousands of female employees at Colorado Plants have been given awareness pins and asked to distribute one to an older women.

Corporate Commitments

* **American Airlines**

  Provide mobile mammography units for 100,000 employees during October.

  Develop promotional materials for in-flight videos that educate passengers on the value of early detection, including the MMI message.

  Distributed information in honor of Breast Health Awareness Month through 3 mailings sent to 75,000 employees.

* **American Association of Health Plans**

  Encouraged and facilitated the distribution of MMI materials to consumers and providers at state health fairs and clinics coordinated by member health plans across the country.

  Distributed information about the MMI to nearly 500 Directors of Communication at member health plans and affiliate state HMO associations.

  Published a public service announcement in the November/December 1997 issue of HealthPlan, a bi-monthly magazine with nearly 8,000 subscribers.

  Showcased the MMI in the May/June 1997 edition of the Medical Affairs Issues Report which reaches nearly 1,000 health plan chief executive officers and medical directors.

* **American Greeting**

  Present Point-of-Purchase display for use in Mother's Day cards that includes a special "reminder"card in greetings that reaches 30,000 stores.

* **BE & K Engineering**

  Provided on-site mammograms for a nominal amount to employees, retirees and their spouses along with other preventive tests during annual wellness fairs.

* **Chrysler Corporation**

  Conducts special corporation-wide education programs on breast cancer awareness. This program is available at 32 Wellness Offices and 72 other corporate locations.

  Distributes 7,000 Shower cards for breast self-examination.

  Chrysler Times awareness feature on Initiative to reach over 200,000 employees and retirees.

  "Tel-A Friend" notice posted in Chrysler locations encouraging employees to telephone their mothers, sisters, friends, and co-workers to remind them of the importance of mammography. For

every person an employee calls, Chrysler will award them one "Wellbuck (an incentive to Chrysler makes available to employees to encourage a healthy lifestyle.).

* **Direct Selling Association**

  Coordinates efforts among over 2600 executives of direct sales companies to produce materials regarding mammograms for circulation. This effort has the potential to reach 6 million direct selling women through monthly magazines, videotapes, audiotapes and payroll and bonus check mailings.

* **Florida Association of Health Maintenance Organizations**

  Conducted free mammograms at the state capitol in March and at Florida area malls the first weekend of each month.

  Provides a toll free telephone number for breast screening information.

* **Food Marketing Institute**

  Developed a brochure with National Cancer Institute, National Urban League and the U.S. Department of Health and Human Services. The National Urban League will distribute the brochure to 114 National Urban League affiliates, and the Food Marketing Institute will distribute it to 1500 members, including their subsidiaries--food retailers and wholesalers as well as their customers in communities across the country.

* **J.C. Penney**

  Distributes information through an insurance policy holder newsletter that reaches 1 million people.

  Distribute message in their October credit mailing that reaches 15-20 million.

  Distribute materials through Eckerd Drug Stores that reaches 2800 stores.

* **Maidenform, Inc.**

  Place 11/14 posters/signs with MMI message in dressing rooms in 100 outlet stores for Mother's Day.

* **National Association of Chain Drug Stores**

  NACDS member pharmacies will participate with American Greetings in a special Mother's Day outreach program, as well as provide information to 88,000 chain pharmacists in over 30,000 chain operated community pharmacies about the Medicare benefit and referral sources.

* **National Community Pharmacists Association**

Published an article, which included the availability of materials, in October 1997 NCPA Annual Convention issue of America's Pharmacist, which reached nearly 40,000 independent community pharmacies via mail. An additional 5,000 issues will be distributed on-site at the October '97 annual convention.

Publish article on the Initiative in October '97 issue of the NCPA Newsletter.

Announced the White House Medicare Mammography Initiative during the General Session of the NCPA Annual Convention in Denver,, October 25-29, 1997.

Post information on the Initiative on the NCPA web site [www.mepanet.org].

Broadcast programming, ads, or general announcement on our soon to be launched in-store television network, NPTV, which will reach hundreds of pharmacies and hundreds of thousands of consumers.

* **Pitney Bowes**

Provide on-site mammograms for female employees over 35.

Work with area hospitals on providing mammograms for uninsured and indigent women.

* **Shaklee Corporation**

Mailed notices to its 14,000 independent distributors and to all its employees alerting them to Breast Cancer Awareness Month.

* **The Longaberger Company**

For every Horizon of Hope Basket purchased, the company donates $2.00 to breast cancer research and education awareness project. Each basket contains a reminder sticker for an annual mammogram that reaches over 2.5 million women.

Publish article on the Initiative in Company newsletter that reaches 40,000 sales representatives.

* **Tupperware Corporation**

Sent memorandum to approximately 1,000 U.S.-based Associates on the importance of regular mammograms and highlighting women 65 and older and the Initiative.

Developed poster with Initiative message to be highlighted at the Tupperware's U.S. Distributor Conference which reaches 350 franchised distributorships supporting the sales force in the U.S.

Published an article on the Initiative in Distributor Bulletin insert that is distributed to the entire U.S. sales force, of approximately 100,000 women.

* **1-800-Flowers**

  Develop a mailer insert with the Initiative message that will be included in a reminder package to be sent to approximately 18,000-20,000 consumers.

Medicare Mammography Initiative
Room 180, OEOB
July 9, 1998

List of Participants

American Association of Health Plans	Barbara Lardy, MPH
American Greeting	Jill Froula
	Sara Gaveames
BE & K Engineering	Donna Sanborn
Direct Selling Association	Neal Offen
Eastman Kodak Company	Jane Carolyn Hasselkus
Eli Lilly & Co.	Irene M. Brandt
Florida Assn. of Health maintenance Organizations	Sharon Cooper
Food Marketing Institute	Dagmar T. Farr
	Natalie Webb Payne
J.C. Penney	Richard Gill
Nat. Assoc. of Chain Drug Stores	Phil Schneider
Nat. Community Pharmacists Assoc.	Douglas Hoey
Pitney Bowes	Patricia A. Sweet
Provalent Communications	Tamar Small
Shaklee Corporation	Charles Orr
Zenecca	James P. Schlicht
1-800 Flowers	Donna Iucolano

National Cancer Institute
Office of Cancer Communications
Consumer Health Profiling Project

Knowing your audience is key to developing successful public education programs. To help identify and understand its target audiences, the National Cancer Institute's Office of Cancer Communications (OCC) uses a unique database that combines health behavior information with geographic, demographic, and lifestyle data. Information from the database is used to create **Consumer Health Profiles** which give a portrait of the "lifestyle clusters" or groups most in need of cancer prevention and detection messages.

Consumer Health Profiles describe the following:

WHO is most in need of outreach, e.g., which areas of a state have the lowest cancer screening rates

WHERE they live, by providing maps

HOW to reach them, by providing information regarding their lifestyle characteristics, media habits, and knowledge, attitudes, and beliefs about cancer.

Consumer Health Profile Reports use information from Inforum, Inc. and Claritas, including:

PULSE (Inforum, Inc.'s annual health care utilization survey of 100,000 households)

US Census Data

National Health Interview Survey (cancer supplement data)

Simmons Market Research Bureau (annual survey of 20,000 American adults, one of the fundamental marketing databases used by advertising agencies)

PRIZM "Lifestyle Cluster System" (developed by Claritas)

What are the "**Lifestyle Clusters**?"

All neighborhoods in the United States have been designated as one of 62 lifestyle clusters of neighborhood groups. These clusters were created through multivariate analysis of the 1990 Census data.

Each cluster is defined on the basis of residents' social rank, mobility, ethnicity, family life cycle, and housing style. Examples of cluster names are Suburban Sprawl, New Empty Nests, and Mines and Mills. These names are catchwords or mnemonic devices rather than literal descriptions. Cluster definitions are adjusted annually and are completely updated following each US Census.

There are two premises underlying the geodemographic clustering concept:

a) People living in the same neighborhood are likely to have similar lifestyles, i.e., they are likely to buy the same products, read the same magazines, support the same causes, and have similar knowledge, attitudes and behaviors related to health.

b) A neighborhood cluster of a particular type will have the same lifestyle characteristics regardless of where that cluster is located geographically, i.e., people living in households of a particular cluster type in Florida are likely to have similar habits and attitudes to households of the same cluster type in Illinois.

Consumer Health Profiles are useful not only in locating your target audience, but also in providing an understanding of your audience that is not provided through demographic segmentation alone. The following illustrates that while two clusters may be similar demographically, they can be quite different in their health attitudes, lifestyles, and media habits. These differences have implications when designing education and outreach efforts.

OLD YANKEE ROWS

Age 65+
Grade School
Asian & Hispanic
$28,000 median HH income

More likely to:
- have Medicare/Medicaid
- rate health status as POOR
- have heart problems and diabetes
- play lottery/go to casinos
- belong to a union
- watch TV sports
- shop at Macy's and Woolworth's

SINGLE CITY BLUES

Age <24, 65+
Grade school
Asian
$18,000 median HH income

More likely to:
- have no insurance
- rate health status as GOOD
- have used a telephone health information service
- paint, draw, sculpt
- belong to a book club
- watch news & feature films
- shop at Woolworth's

THE MEDSTAT GROUP

INFORUM
Success Stories

NCI Uses Cluster Profiles for Cancer Education

The National Cancer Institute (NCI), located in Bethesda, Maryland, is the nation's primary agency responsible for cancer research. Its Office of Cancer Communications (OCC) is responsible for communicating cancer research findings to the public. The OCC uses a social marketing approach to develop programs for patients and the public, with a special focus on underserved populations in need of cancer education and outreach programs. These education programs are implemented primarily through NCI's Cancer Information Service (CIS), a nationwide network of 19 regional offices each with a component dedicated to outreach. The CIS works with cancer-related organizations and local media to reach targeted populations with NCI messages.

The Inforum system is an invaluable consumer research tool for the NCI's Office of Cancer Communications (OCC) because it allows the OCC to identify who is most in need of cancer education and outreach programs, where they live, and how best to reach them, according to Melissa Taylor, Health Marketing Specialist for OCC.

The OCC recently began a new initiative, the **Consumer Health Profiling Project,** to assist public health program managers and state health departments in planning regional and local initiatives. The project consists of demographic and cluster maps used in conjunction with Cluster Profiles. Together, they help program planners understand and choose audience segments, thereby increasing the effectiveness of public health interventions.

The Cluster Profiles are hard-copy documents that provide a portrait of the audience segments in the CIS's 19 regional offices who are "most in need" of cancer education and outreach programs. In total, the OCC identified 23 clusters with higher-than-average concentrations of minority, low-income and older residents (55+) based on variables such as race/ethnicity, household income, and age. Targeted clusters included those with a high concentration of women ages 55 and older who had not had a mammogram in the past year. The Cluster Profiles were compiled from information provided by the Inforum system, which integrates data from a variety of sources including Claritas Corp.'s PRIZM Lifestyle Segmentation System, the National Health Interview Survey, Inforum's PULSE Survey, the U.S. Census and Simmons Market Research Bureau.

"The Cluster Profiles provide a wealth of information about audiences most in need of a variety of cancer education and outreach programs," Taylor said. "Based on information from the Inforum system, the profiles provide reviews of healthcare attitudes, beliefs and behaviors, media habits and lifestyle characteristics of these audiences. This means that tailored outreach programs can be developed and implemented more effectively. In particular, this information can be used to identify knowledge gaps among audiences, mass media outlets for placing cancer-related messages, and locations for placing flyers and posters."

The Idaho State Department of Health and Welfare recently used the Cluster Profiles to buy media time for an ad campaign designed to let people know about publicly-funded programs and to encourage women to get an annual physical. "Every time the ads run, our toll-free switchboard lights up," said Minnie Inzer, Project Coordinator for the department's Breast and Cervical Cancer Early Detection Program. "Our local mammography facility is booked several weeks out, as a result."

Paul VanNevel
Assoc. Dir.
of Cancer
Communi.
NCI
Bldg 31
10A29
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Booklet, "Campaign: Vote Breast Cancer," 24 pages

CAMPAIGN: VOTE BREAST CANCER

1998 Voting Record

NBCC

NATIONAL BREAST CANCER COALITION