4/12 Susan Wood

- working w/ AHA on developing risk assessment tools on Web for ♀ to assess their risk

how do we focus on ♀ + Heart disease
maybe not a task force

launching – May – big media campaign
for ♀ of color – "p. de your path"
all health issues – diabetes, heart disease

as boomers become menopausal, heart disease became a big issue
knowing that symptoms are diff. for ♀ than ♂ —
you + provider need to be aware.

→ educating prevention, provider awareness

Wise Woman – add on to Breast + Cervical Cancer screening
while they have ♀ – for hrs ↑, do
cholesterol, BP, blood sugar screenings
3 states demonstrations – – 80% are at risk for HD

②

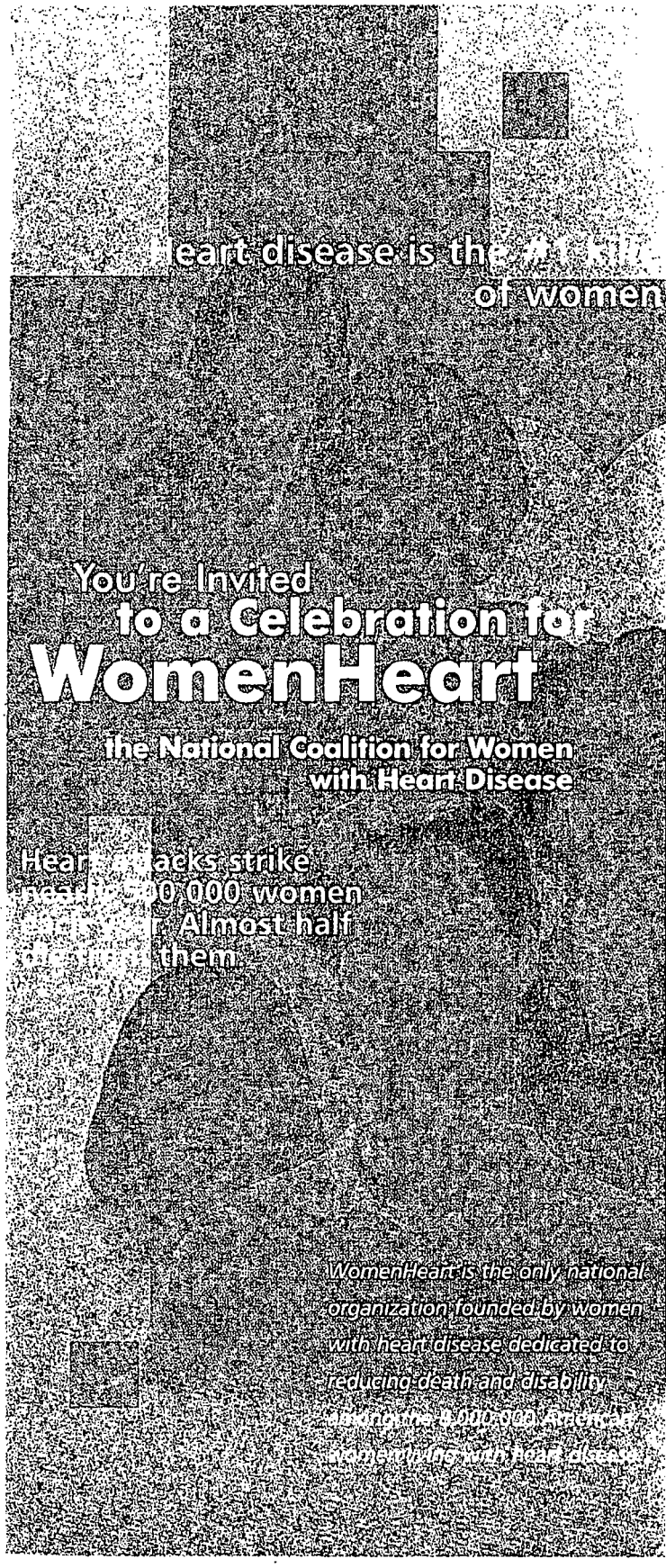
Cancer cluster research →

S.F. + LI clusters

Steve Morin - pt ū [illegible] for CDC, NCI + [illegible] –

$ 15 million no year $

Congress directed them to spend on affected areas
doesn't know if it went to where intended –
NCI took $ + ran


eart disease is the #1
of women
You're Invited
to a Celebration for
WomenHeart
The National Coalition for Women
with Heart Disease
Hear acks strike
0,000 women
Almost half
them.
WomenHeart is the only national
organization founded by women
with heart disease dedicated to
reducing death and disability
among the 4,000,000 American
women living with heart disease

womenheart

the National Coalition
for Women with Heart Disease

cordially invites you to our
Kick-off Celebration Luncheon

and inauguration of our Annual Awards
for excellence in

Advocacy

Communications

Community Education

Corporate Leadership

Healthcare

Public Policy

hosted by
Doreen Gentzler
News Anchor, NBC Channel 4

Monday, April 3rd
12 noon

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Darcy Hemley photography

SAVE AND POST!

WOMEN: Know your heart attack warning signs...

- Dizziness or nausea.
- Clammy sweats, heart flutters, or paleness.
- Unexplained feelings of anxiety, fatigue, or weakness, especially with exertion.
- Stomach or abdominal pain.
- Shortness of breath and difficulty breathing.
- Pressure or pain that spreads to upper back, shoulders, neck, or arms.
- Discomfort, fullness, tightness, squeezing or pressure in center of chest that stays for more than a few minutes or comes and goes.

If you are having several of these heart attack warning signs...

- Call 911 for an ambulance or have someone drive you to the nearest hospital emergency room immediately. Do not delay! Tell the hospital staff that you are having heart attack symptoms.
- Insist that the hospital staff takes your complaints seriously, does not make you wait, and gives you a thorough cardiac evaluation including an electrocardiogram (EKG).
- Chew and swallow with water one regular full-strength aspirin as soon as possible to prevent blood clotting.
- If the initial evaluation shows you have not had a heart attack, you could still have blocked arteries. Talk with your doctor about your need for further evaluation with tests, such as a treadmill stress test or visit a cardiologist for a more complete examination.

Early detection and treatment of heart disease can prevent many heart attacks. Talk to your doctor about your risk factors and family history of heart disease. Get your cholesterol, triglycerides, and blood pressure checked regularly. Please, don't become a heart disease statistic.

WomenHeart
1718 M Street, #330
Washington, DC 20036
Tel: 202-736-1770
www.womenheart.org

BASS AND HOWES INC

WomenHeart

Strategic Plan

✧✧✧

Developed by

BASS and HOWES, Inc.

January 14, 2000

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INTRODUCTION

Heart disease is the greatest health risk and the leading cause of death for American women - contrary to a public perception that it only affects men. Despite the incidence and severity of the disease, heart disease in women is only beginning to receive serious attention from the health community and the media. Incorporated in March 1999, WomenHeart is the first and only national non-profit organization run by and for women with and at-risk for heart disease.

In the few months since WomenHeart was founded, the Board of Directors has made tremendous progress toward building a credible and well-respected organization. Even before the organization has been publicly announced, it has begun to generate a buzz in the media and with major corporations and key opinion leaders in women's health. Some of the organization's major milestones to date include:

- A high-profile article featured in the November 1999 edition of *Fortune* magazine.
- Assembly of a large and prestigious advisory board of opinion leaders from the field of women's health, academia and public policy.
- Formation of a corporate advisory board.

Every day, WomenHeart gains momentum. The Board of Directors has a bold vision for this organization and is working energetically to move WomenHeart forward. They continue to establish and strengthen relationships with current and potential funders and partners. The Board is planning for the organization's public launch and the flood of activity that will follow as well as preparing to build the infrastructure to support a major organization. Because of their tireless efforts, WomenHeart is positioned to become a major player on the national level and to provide much-need information, support and advocacy for the 8,000,000 women in America living with heart disease.

BASS and HOWES was hired by WomenHeart to develop a strategic plan to guide the organization's growth over the next two years. This document focuses on the key programmatic and organizational goals and objectives that are critical to moving the organization forward. The plan is informed by interviews BASS and HOWES conducted with several members of the Board of Directors and Advisory Board during December 1999 and January 2000.

THE PROBLEM

Heart disease is the leading cause of death for American women and their greatest health-risk. Despite the fact that half of American women die of cardiovascular disease (heart disease and stroke) and 220,000 women die of heart attacks each year, women are largely unaware of their risk for heart disease. According to the National Center for Health Statistics, 46% of women consider breast cancer to be their most serious health threat while only 4% of women consider heart disease their most serious threat. In actuality, breast cancer kills only 4% of women while heart disease kills 36%.

Heart disease suffers from a particular stigma among women - who often perceive it as a lifestyle disease. Because both behavioral and genetic factors determine risk for heart disease, women tend to feel embarrassed and guilty to be suffering from a disease they might have been able to prevent. In addition, there is a fear of employer discrimination as an employer may consider an employee with heart disease frail and unable to accomplish the tasks required by her job. This shame and worry contributes to a collective silence about women and heart disease. Women diagnosed with heart disease tend to hide their condition from their friends, neighbors, coworkers and employers and they seem to be less likely than men to access support services. Unlike the breast cancer movement, women with and at-risk for heart disease lack sources of accurate information, a public presence and representation at national, state and local levels.

And it is not only women who are misinformed about their risks for heart disease. The health care system has compounded the problem. Studies have demonstrated an alarming lack of awareness among primary care physicians about the signs and symptoms of heart disease in women, which differ from those in men. This is backed up by a number of recent studies.

For example, a 1996 Gallup poll found that nearly two-thirds of primary care physicians reported "no difference" in the symptoms, warning signs, and diagnosis of heart disease in women, compared to men. In fact, only 10% of providers in this survey correctly identified nausea, dizziness and swollen ankles as symptoms of heart attack in women. Studies have revealed a lack of awareness among primary care providers about diagnostic tests for heart disease in women and even about the prevalence of heart disease in women. It is no surprise that some women report that their physician has not recognized a heart attack. Furthermore, studies have shown that women in recovery from a heart attack are less likely to receive certain treatments, including angioplasty, and are less likely to be referred to cardiac rehabilitation. In short, women are less likely than men to be screened for heart disease, counseled about risk factors and diagnosed early-on with the disease.

WomenHeart will give voice to and empower the large but so far silent population of women with and at-risk for heart disease. Through highly visible campaigns at the national level, WomenHeart

will convey the message that heart disease does not belong to men -- that women are at equal risk for this serious and often deadly disease. WomenHeart will empower women with information about risk factors and ways to prevent heart disease and treatment options. In addition to encouraging women to talk to their doctors, WomenHeart will go straight to the health care community to press for more serious attention to the issue of women and heart disease.

LONG-TERM VISION AND GOALS

The ambitious long-term goal of WomenHeart is to reduce the morbidity and mortality of heart disease in women. The organization will do this by pursuing three parallel strategies:

- **Providing information and support to women with and at-risk for heart disease**
  For women with heart disease, WomenHeart will be the place to turn to for support and information, and to connect with others like them. On its website and in communities across the country, WomenHeart will connect women to each other online, through chat rooms, and in person through community support groups. As a reliable source of information about heart disease, heart-healthy behaviors, trends in heart disease research, treatment options and other issues of interest, WomenHeart will also serve a broader community of family, friends, providers, researchers and policy makers.

- **Raising public awareness about women's risk for heart disease**
  WomenHeart will work through traditional and new media to raise public awareness of women's risk for heart disease. Online, in magazines, newspapers, and on television, WomenHeart will promote messages that encourage women to know their risk factors for heart disease and to talk to their doctors.

- **Giving voice to women with heart disease**
  Working through the health care system and in Washington, WomenHeart will promote the interests of women with heart disease by advocating for policies that will improve access to and quality of services for women with and at-risk for heart disease and for gender-based research on heart disease in women. WomenHeart has the potential to be the premiere organization advocating on these issues and can become an influential force on Capitol Hill.

YEAR ONE GOALS AND OBJECTIVES

In the first year, the organization's primary goals will be to get the word out that it exists, to build a credible reputation, to launch programs and to begin to build the organization's infrastructure.

Over the next year, WomenHeart can take several important steps that will significantly move the organization forward toward accomplishing these goals:

- Launch a two-tiered program to support women diagnosed with heart disease and women in recovery from a heart attack and to raise awareness and promote early detection of heart disease in women.
- Lay the groundwork for an advocacy program.
- Hire Executive Director and support staff and secure office space.
- Build a membership base of women with heart disease.
- Develop a long-range fundraising plan.

These first-year goals are discussed in further detail below and are broken out by programmatic and organizational goals.

PROGRAM GOALS

The first year will be a learning period for the organization about its constituencies, their needs and how WomenHeart can best serve them. In the first year, we recommend WomenHeart focus on its primary audiences of women with and at-risk for heart disease. These women will be WomenHeart's driving force and its greatest asset. This year, WomenHeart's priority should be to reach out to these women, bring them into the organization and to get to know them. As the organization grows, it can begin to reach out to its secondary audiences of health care providers, family members and friends, managed care and health insurance firms, policy makers and other government officials.

This section lays out important goals toward launching WomenHeart's program for women with or at-risk for heart disease.

GET TO KNOW CORE CONSTITUENCIES

WomenHeart has three distinct core constituencies:

- women in recovery from a cardiac event or surgery
- women diagnosed with heart disease or diagnosed as at-risk for heart disease
- women with or at-risk for heart disease, but undiagnosed

Each group is in a different place with respect to their interest in an organization like WomenHeart and the degree to which they are paying attention to heart disease and their needs for information and support. An important first step in planning programs and activities to serve the organization's core constituencies will be getting to know who these women are, how to communicate with them and what they need.

We recommend that WomenHeart conduct a series of focus groups with women from each of these constituencies. Focus group research can help WomenHeart to better understand:

- Women's attitudes, beliefs and knowledge about heart disease, including risk factors and treatment options.

- Why there is a stigma associated with heart disease in women and what messages might help to counter the stigma.

- Specifically for women at-risk, what messages would motivate them to assess their risk factors for heart disease and talk to their doctors.

- For women diagnosed with heart disease and in recovery, what kinds of support and information they would like from an organization like WomenHeart.

In addition, we recommend that WomenHeart conduct a national public opinion survey about women's attitudes, perceptions, and behaviors related to heart disease. The survey will establish:

- What women currently know about heart disease in women. This information can be broken down by age, race, income and education levels and geographic location. Minority groups should be oversampled in the survey to ensure adequate data for analysis.

- Where they get their information about heart disease (magazines, newspapers, television, Internet, health care providers, etc.).

- What they are doing to prevent heart disease or what behaviors they have that put them at greater risk for heart disease.

Results of the research will help:

- Guide messages and strategies for programmatic activities.
- Establish a baseline against which the organization can measure its progress toward increasing awareness and changing perceptions about heart disease in women.
- Enable WomenHeart to make a substantive contribution to the scientific and provider community by adding to its knowledge base.
- Provide something newsworthy and substantive for WomenHeart to announce at its launch.

DEVELOP AND IMPLEMENT PROGRAMS THAT SERVE CORE CONSTITUENCIES

For the purposes of planning programs, we recommend WomenHeart group together women in recovery from a cardiac event with women diagnosed with heart disease because these women's support and information needs are likely to overlap significantly. The organization already has in place a sophisticated and comprehensive website to provide information and support to women with heart disease and in the first year, the website will continue to form the core of the organization's support services.

1. Women with Heart Disease and in Recovery from Cardiac Event

Women with heart disease and in recovery from a cardiac event are WomenHeart's natural constituency. Like the founders of WomenHeart, these women are living with a serious disease and in need of the supportive and informational services that WomenHeart can provide.

WomenHeart's main challenge with this population over the next year will be to figure out how to get the word out that WomenHeart exists and is a resource for them. A major media campaign will obviously be an important component of WomenHeart's outreach efforts. Other possible strategies include: links to WomenHeart's website from other websites these women are accessing; patient education brochures disseminated through cardiologists' offices and support groups; and, announcements in member publications of Advisory Board members' and others' organizations.

Some of the strategies WomenHeart might use to support these women follow.

Website: WomenHeart's website will be a place where women can go at any time for information and support. The website can help WomenHeart create an online community of women with heart disease through chat rooms in which they can interact with each other. WomenHeart can sponsor regular "talk to the experts" sessions on the chat rooms to provide women with the opportunity to converse online with researchers, clinicians and others about topics of interest. Chat room discussions will be archived on the website so that visitors can browse previous discussions.

Working in Communities: In addition to reaching women online, WomenHeart should go into communities to reach out to and support women at the local level. In the first year, the organization should select three to five target communities in which to develop and implement pilot projects that can be tested and rolled out at the national level in year two. Because of the concentration of heart disease in the South, we recommend targeting two cities in this region.

The kinds of activities WomenHeart sponsors at the local level will be guided by the focus group research on what these women need and by the resources available in the communities. Some possibilities include:

> **Support Groups**: There is a great need for the establishment of support groups for women with heart disease. By connecting women with heart disease to each other, support groups can help to erase feelings of isolation and provide an opportunity for women to support and be supported by people who are sharing similar experiences.
>
> WomenHeart can promote support groups by creating a turn-key kit to guide women on how to develop and maintain groups in their areas. The kit could also be posted online.
>
> **Walking Program**: WomenHeart might sponsor a program to promote walking, which is an easy and inexpensive way for women in recovery to improve their health and reduce stress and provide an opportunity for women to interact with each other on a regular basis. This kind of program could be developed in partnership with rehabilitation programs at local hospitals and clinics.

Media/PR: In the cities where WomenHeart is active, we recommend WomenHeart hire a media relations firm that can help to place stories in local media about WomenHeart's activities.

2. **Women At-Risk for Heart Disease**

In comparison to the first audience, this group of women is much larger and more generic and presents a very different challenge in terms of outreach. Studies show that women in general are not concerned about heart disease, and are largely unaware of the prevalence, risk factors, signs and symptoms of heart disease in women.

The goal with this group of women will be to raise their awareness about their risk for heart disease, to encourage them to know their risk factors and to talk to their doctors about how to prevent heart disease and to make them aware of WomenHeart, a place where they can turn to for information about heart healthy behaviors.

The challenge with this group will be capturing their attention. Unlike women diagnosed with heart disease or in recovery, they are unlikely to be paying attention to this issue. WomenHeart's strategies will have to be more creative and innovative to break through the clutter. The focus group research will help WomenHeart identify the messages and strategies that are likely to have the greatest impact.

This is also an extremely large audience and WomenHeart's capacity to reach them in a significant way will be dependent on resources. There is, however, tremendous opportunity for WomenHeart to partner with major corporations, associations, and non-profit organizations.

Launch: WomenHeart's launch will announce the organization at the national level, and provide the first opportunity for WomenHeart to raise awareness of the organization among its primary and secondary audiences.

We recommend that the launch be the venue at which the results of the survey are announced. The survey results will give the organization something substantive and noteworthy to announce and will enhance the organization's image as a serious organization. In addition, as the survey and focus group research will help WomenHeart fine-tune its program, scheduling the launch after the research is completed will allow the organization to announce in a more concrete way what it will be doing for women with heart disease.

Involving a few key members of the Advisory Board would make the event even more noteworthy and would enhance the WomenHeart's image as a credible organization. For example, if the event was structured as a media roundtable on women and heart disease, experts from the Advisory Board could be invited to participate in the conversation.

If major funding comes through, WomenHeart could sponsor other major public awareness activities, events and/or campaigns this year. We recommend that WomenHeart continue to have the kinds of conversations it is having with pharmaceutical companies and other potential corporate sponsors to flesh out ideas of mutual interest.

To maximize the impact of these kinds of activities, strategic partnerships should be formed with organizations that can broaden WomenHeart's reach. Obvious partners would be those represented on WomenHeart's Advisory Board, such as the YWCA , the National Black Women's Health Project and others.

Some of the kinds of activities that WomenHeart could sponsor in partnership with a major corporate funder and other non-profit organization include:

- Nationwide screening day
- Women's heart walk in major cities
- National walk day
- Exhibit at major women's health fairs
- Partner with local libraries to help women access information via the Internet
- Public Service Announcements

LAY GROUNDWORK FOR ADVOCACY PROGRAM

As a unique organization run by and for women with heart disease, WomenHeart is in a position to become the premiere organization representing the interests of this constituency to policymakers. WomenHeart is positioned to best understand the needs of women with heart disease and to advocate for the policies and resources to meet those needs.

The first step WomenHeart needs to take to become an influential advocate is to build a reputation in Washington as a credible organization and source of accurate information about women and heart disease. WomenHeart can begin to build this reputation by introducing itself to the key players including Members of Congress, their staff, Administration officials, and professional organizations, such as the American Medical Association and the American College of Cardiologists. Advisory Board members could be a very valuable resource as they could help WomenHeart gain access and interested members might participate in visits with WomenHeart to some of these key people. In addition, WomenHeart should establish relationships with other voluntary health associations and explore opportunities for participation in coalitions and networks.

Part of finding WomenHeart's niche will be defining itself vis-a-vis some of these other national organizations that are concerned with heart disease in women, particularly the American Heart Association. WomenHeart should build its relationships with these organizations to ensure that WomenHeart's activities build on and are complementary to other efforts and to explore opportunities for collaborative activity in year two.

Secondly, WomenHeart should begin to flesh out a policy agenda. Levels of funding for research and how research money is spent is an obvious area in which WomenHeart will want to weigh in with Congress and the Administration. In addition, a number of other issues may come up that affect women with heart disease, which could be related to access and quality of care. Over the next year, WomenHeart should work with experts on its advisory board and others to monitor trends in heart disease research and to identify the organization's advocacy priorities. Additionally, WomenHeart should continue to initiate and maintain relationships within the research community, particularly at the National Heart Lung and Blood Institute.

With these pieces in place, WomenHeart can launch its advocacy program (see Year Two), which would likely involve educating policymakers about heart disease in women, lobbying on Capitol Hill on appropriations for heart disease research and participating in coalitions on other issues that affect women with heart disease. WomenHeart should keep its members and other stakeholders appraised of its advocacy work and should cultivate grassroots advocates within its membership.

ORGANIZATIONAL GOALS

This section lays out the operational tasks WomenHeart will need to undertake in the coming year to build its capacity to carry out programs. These include building an infrastructure, staffing the organization, resolving governance issues, creating a membership database, developing a long-term fundraising strategy and determining the role of the Advisory Board.

HIRE STAFF AND BUILD INFRASTRUCTURE

Staffing WomenHeart and beginning to build organizational infrastructure should be a high first year priority in line with the organization's first year goal of becoming an official organization with a credible reputation. As soon as resources allow, an Executive Director should be hired and office space secured. In addition, WomenHeart will need support in the areas of website maintenance, fundraising, program development, communications/press, and database creation and management. Depending on resources, these functions can be carried out in the first year by a combination of support staff and consultants.

EXPAND BOARD OF DIRECTORS/CLARIFY ROLE

Over the next few years, the Board of Directors will play a critical role in helping WomenHeart to grow and hit its stride as an organization. In order for the Board to govern most effectively, it will be important for members to devote a significant amount of time early on developing consensus and clarity about the Board's role and the lines of authority between itself and the Executive Director.

First, the Board will have to consider what kind of Board it wants to be and what its role will be in governing the organization. There are a number of models of non-profit Boards, each of which has unique strengths. Some possibilities include:

- **Policy Boards** determine the overall direction of the organization, deciding who the organization will serve, how and at what cost. They authorize the executive of the organization to accomplish the goals they set forth. These boards tend to be made up of a small group of dedicated individuals who are comfortable with focusing on the big picture and leaving the implementation to the organization's staff.

- **Stakeholder Boards** are comprised of the population the organization serves (in this case, women with heart disease). In addition to guiding the overall direction of the organization, they are more active in the organization's governance and the implementation of programs.

- **Blue Ribbon/Fundraising Boards** tend to be largely prominent individuals whose affiliation with the organization brings it credibility and who, because of their position and access, can raise money or open doors for the organization. Usually these Boards have a more involved executive committee that makes policy decisions and governs the organization.

These options are not mutually exclusive, and many organizations choose to adopt a variation of these models. Furthermore, many boards evolve over time as their organizations grow. We recommend that the board meet early in the year, if possible with a professional facilitator who has organizational management experience, to come to consensus about its role.

Once the Board has determined its role, it can work toward another important first year goal: to expand and diversify the Board to include people with varied experience and backgrounds. Members of the Board have already begun to recruit new members from different ethnic backgrounds, especially those most affected by heart disease, which include African Americans and Hispanics.[1] We recommend the Board continue to move forward in this area and involve members of the Advisory Board who could be helpful identifying candidates from these communities.

BUILD MEMBERSHIP

WomenHeart's strength as an organization representing and serving women with and at-risk for heart disease will come from its membership. While membership will be open to women with and at-risk for heart disease, as well as family members and friends, health care providers, researchers and advocates, the core membership is likely to be women diagnosed with heart disease and women in recovery from a cardiac event or surgery. These are the people with the greatest stake in this organization and the most likely to decide to actively join as members.

WomenHeart's founders have determined that membership in the organization should be free to all who wish to join. At least during the first year, new members will be captured primarily through the website which provides an online membership form. In the future, people might also sign up through an 800 number or on-site at community activities.

When somebody becomes a member, they have the option of receiving the WomenHeart's free email newsletter, available information on services for women with heart disease in their community, and

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[1] According to the National Institutes of Health, heart disease is the leading cause of death among African American and Hispanic females. It should also be noted that while the incidence of heart disease is lower for American Indian and Asian American women, it is the leading and second leading cause of death respectively for these populations.

an email message from Coalition sponsors. With updates about its activities, additions to its website, announcements of online chat sessions with experts, information about community activities, news about trends in policy or research, the email newsletter can be a regular reminder that WomenHeart is the place to turn for anything related to women with heart disease.

In addition, when people sign up as members, they will be provided an opportunity to indicate ways they would be interested in being actively involved in the organization's efforts, including by coordinating support groups, serving as media spokespeople and helping with fundraising. Members can be a valuable asset to the organization in these capacities and WomenHeart should leverage this resource as much as possible. At some point in the future, WomenHeart may want to have some sort of regional structure similar to chapters but perhaps less formalized. Working with members in the capacities listed above will help WomenHeart to identify early on who its local leaders are who can later be tapped for the development of regional networks.

We recommend that WomenHeart develop a membership database to track of the names of members and the ways they want to be involved. In addition, WomenHeart should maintain a database of people who contact the organization but do not join as members. These databases will be useful in future fundraising campaigns and in any grassroots advocacy activities WomenHeart organizes.

DEVELOP FUNDRAISING PLAN

Although WomenHeart is still a virtual organization, a number of corporation have expressed interest in partnering on events and programs. We believe this is a reflection of the great need for and promise of this organization. However, this level of interest from potential funders this early in the organization's development presents both a challenge and an opportunity. In particular, it is important for the organization to avoid the appearance of reflecting a particular donor's agenda.

Diversifying WomenHeart's funding base will lessen the organization's dependency on any one funder and will increase the organization's financial stability over the long-term. A diversified funding base might include grants from corporate and other foundations, government grants, and individual donations from members, supporters and large corporations.

We recommend that over the course of the next year, WomenHeart develop a long-range development plan for sustaining the organization and diversifying its funding base. A fundraising consultant with non-profit development experience can help to create the plan. Additionally, when resources allow, WomenHeart should hire a staff person with nonprofit development experience to develop a fundraising plan, materials and contacts.

ADVISORY BOARD

WomenHeart has assembled a large and prestigious advisory board of opinion leaders and experts from the field of women's health. In addition to giving the organization a large degree of credibility, these women have the potential to be a tremendous resource to WomenHeart in a number of ways. An important goal for next year should be to introduce WomenHeart to the Advisory Board, get them engaged in the organization's mission and program and determine how the Board can help WomenHeart advance its goals.

Advisory Board meetings will give WomenHeart a valuable opportunity to get feedback and input on mission, strategies and tactics from a diverse panel of experts. Clinicians in the field can guide WomenHeart on where there are gaps in service for women with heart disease, academics can advise on latest trends in research and advocates can provide guidance on political strategies.

While the busy schedules of some members will only allow them to participate in Advisory Board meetings, others may be interested in taking a more active role in this organization. In fact, in our conversations with select members of the Advisory Board, some members expressed a commitment to taking a very active role. Depending on their interest and background, some Advisory Board members could serve in any of the following roles:

- Spokespeople for the organization on Capitol Hill and with the media.
- Reviewers to ensure the scientific accuracy of WomenHeart's written materials.
- Guest experts in special online chatrooms.
- Authors of policy papers or position statements on priority issues.
- Partners in the development and implementation of programs.

The first meeting of the Advisory Board will provide members the opportunity to get a better vision of WomenHeart and to think about how they might be involved. We recommend that WomenHeart send Board members a survey following the first meeting to gauge members' level and areas of interest in working with WomenHeart between meetings.

YEAR TWO GOALS AND OBJECTIVES

Because WomenHeart's development over this year will be dynamic and evolving, it is difficult to accurately project the second year at this time. Where the organization is a year from now will largely be determined by the resources it has available and the opportunities that arise over the course of the year. However, there are a number of areas in which it will be important for WomenHeart to continue to move forward in order to take the organization to the next level both in terms of program and infrastructure.

CONSTITUENCIES

While we recommend focusing on its core constituencies of women with and at-risk for heart disease in the first year, the organization will also be laying the groundwork for reaching out to its secondary audiences and stakeholders, which include health care providers, family members and friends, policymakers and managed care and health insurance firms. In the second year, WomenHeart can begin to reach out to these audiences in a purposeful way.

SIGNATURE EVENT

By next year, WomenHeart should have the capacity in terms of membership, resources, staffing and organization to sponsor a signature event or campaign to raise awareness at the national level around women and heart disease and to promote early detection. We recommend that WomenHeart take advantage of February as national heart month and host the event or launch the campaign that month. The event or campaign should be informed by the focus group and survey research about women know about heart disease and what messages are likely to have the greatest impact with them.

The event or campaign should take advantage of traditional and new media and should be developed in cooperation with media consultants and shopped to potential funders over the course of the next year. We recommend that WomenHeart seek multiple funders for this effort.

EVALUATE PROGRAMS AND ROLL OUT AT THE NATIONAL LEVEL

In the second year, WomenHeart should evaluate its programs to serve women with heart disease and in recovery from cardiac events or surgeries, determine which strategies were the most successful and begin to roll them out in turn-key fashion at the national level.

Estrogen Question Gets Tougher

Major Study Casts Doubt on Common Wisdom on Heart Role

By GINA KOLATA

News Analysis

Every time that Marion Nestle sees a new doctor, the awkward question comes up. The doctor looks at her age: 63. The doctor looks at her family history: heart disease. And the doctor asks her why on earth is she not taking estrogen?

"Every encounter with a new doctor involves a discussion about it, not raised by me, raised by the doctor," said Dr. Nestle, who is a professor and chairwoman of the department of nutrition and food studies at New York University. "Are you taking it? Have you considered taking it? At your age, you should be taking it."

Her experience is common, women say. As soon as women approach menopause, their doctors often start asking when they will start taking hormone replacement therapy. And if the woman hesitates, her doctor will often explain that the hormones can protect her against heart disease, the leading killer of women.

But now, a huge federal study of hormone replacement therapy is calling that idea into question and doctors and individual women are trying to deal with the consequences. Phones rang in doctors' offices throughout the country yesterday, and doctors braced themselves for the inevitable questions that would come up in every office visit with a postmenopausal woman.

Women taking estrogen wondered if they had done the right thing. Others who had refused the drug felt vindicated. But the real answer, for now, is that the estrogen question is still a work in progress.

Far from being a medical certainty that hormone replacement therapy protects against heart disease, preliminary data suggest, in fact, that the drugs might cause a slight increase in heart attacks and strokes, at least in the first two years that women take them. The results are sketchy, and the risk, if any, seems very slight.

Dr. Claude Lenfant, director of the National Heart, Lung and Blood Institute, which is running the study, said women taking the therapy should not stop because of it.

But the finding brings to the fore one of the great conundrums of American medicine: a leading reason for using the best-selling drug in America has never been established and might well not be true.

The belief that estrogen protects the heart did not come out of nowhere. Studies comparing heart attack rates in women taking hormone replacement therapy with those who did not found lower rates of heart disease in women taking the hormones. The difficulty, though, is that women who take hormones tend to have a lower risk of heart disease anyway. They are unlikely to smoke, more likely to exercise and they eat healthful diets.

Still, the findings seemed to offer a solid reason for healthy women to take a drug for the rest of their lives. For some, though, the real appeal of estrogen may have been their hopes that it was a path to eternal youth.

Wyeth-Ayerst Laboratories, the maker of Premarin, the best-selling estrogen product, says that while 10 million American women take the drug, it is only approved for the treatment of symptoms of menopause, like hot flashes, and for the prevention and management of osteoporosis, the bone disease many women suffer after menopause. But Lauren Hutton, a supermodel who is featured in company advertisements about menopause, told Parade magazine that estrogen was "good for your moods, it's good for your skin."

"If I had to choose between all my creams and makeup for looking and feeling good" Ms. Hutton advised, "I'd take the estrogen."

Audrey Ashby, a spokeswoman for Wyeth Ayerst, said: "Lauren Hutton speaks her mind about what she believes in. But she is a spokesperson, not for Premarin, but for an unbranded ad that discusses the consequences of menopause and estrogen loss."

Some women who refuse to take the drug say they constantly have to explain themselves. "Everyone I know takes it, practically without exception," Dr. Nestle said. She does not, she says, because, "I read the medical literature and I prefer to be cautious."

Now Dr. Nestle feels vindicated.

A federal official cautions against halting therapy.

The disconcerting finding on heart disease arose in a study, known as the Hormone Replacement Therapy Trial of the Women's Health Initiative, that involves about 25,000 healthy postmenopausal women. They were randomly assigned to take hormone replacement therapy or a dummy medication.

Last Friday, the study investigators sent each of the women a letter, gingerly informing them that those who took estrogen were having slightly more heart attacks, strokes and blood clots in their legs and lungs than those taking the placebo. The total number of women who experienced these serious problems was very small, less than 1 percent of the women. And the effect seemed to fade with time. But, the study investigators said, they had to tell the women about it.

Another recent study, of women who already had heart disease, also found that hormone replacement therapy increased the likelihood of heart attacks and strokes for the first two years. Although the trend reversed itself in that study, the net effect of estrogen was neither to protect nor harm the heart.

Many gynecologists were convinced by the weaker comparative studies, however.

Dr. Nanette Wenger, a cardiologist at Emory University, said she went to a medical meeting recently and tried to explain the questions about hormone replacement therapy and heart disease to an audience of about 700 obstetricians and gynecologists. They were surprised, she said, telling her that they had thought that it was well known that estrogen prevented heart disease. As a result, Dr. Wenger said, "often coronary disease is cited as the reason to prefer estrogen over other therapies."

Some gynecologists say they will continue, for the time being, to recommend that some women take estrogen to protect against heart disease. Dr. Wulf H. Utian, an obstetrician/gynecologist in Cleveland who is the executive director of the North American Menopause Society, said he had and still would use estrogen for that purpose. The new findings, he said, "don't change my stance at all."

Dr. Charles B. Hammond, a professor and chairman of the department of obstetrics and gynecology at Duke University, said "it's way too soon to react" to the Women's Health Initiative study. Hormone replacement therapy "is one tool in the war on cardiovascular disease and a very important one," he said, cautioning that at this point "we have to be very careful not to stampede women based on scanty information."

But some women say their doctors tried to stampede them the other way — into taking the hormones.

"My experience was plain and simple," said Alice Wolfson, a 55-year-old lawyer in San Francisco. Although she has no risk factors for heart disease, she said, her doctor urged her to take the therapy to protect her heart. "My doctor said, 'You should be taking hormone replacement therapy,'" she recalled.

Sarah Grindel, 59, who runs a quilting business with her daughter in Rockport, Mass., saw three doctors, all of whom insisted that she should take estrogen to protect against heart disease, even though her blood pressure is low, her cholesterol level is fine and she has no family history of heart disease. "Every doctor was saying just do it, do it," she said.

Dr. Wenger, a principal investigator in the Women's Health Initiative Study, said yesterday that her office had been inundated with calls from other doctors. "My phone has been ringing off the hook from my colleagues," she said. "Should I let my wife take estrogen? Should my wife continue with estrogen?"

"The answer is that right now, we don't know," Dr. Wenger said. That is why the National Institutes of Health is doing its study.

The New York Times

THURSDAY, APRIL 6, 2000

Council to Ask U.S. to Head Police Inquiry In Los Angeles

By The New York Times

LOS ANGELES, April 5 — Concerned about internecine warfare between law enforcement officials and potential conflicts of interest, the Los Angeles City Council voted today to ask the United States Justice Department to take over the investigation of corruption in the police department.

On a 10-to-1 vote, the city council passed a resolution asking the Justice Department to become the lead agency coordinating the local, state and federal authorities involved in the investigation and prosecution of charges of brutality, evidence planting and false testimony centered in the Los Angeles Police Department's Rampart Division.

The request came on the same day that officials announced the filing of federal civil rights charges against one current and one former Los Angeles police officer from the department's 77th Street station in the South-Central area.

The charges stem from a 1995 incident in which the two officers were said to have planted a gun on an innocent man and had him prosecuted for possession of a concealed weapon. The man, Victor Tyson, was exonerated on a judicial finding of innocence, in which a judge, regardless of a jury's decision, essentially acquits a defendant.

The Rampart scandal was unleashed by the statements of one officer, Rafael Perez, who in exchange for a lighter sentence on charges of stealing cocaine from an evidence locker has told the authorities about widespread corruption at the Rampart Division. Last week, prosecutors went to court to have four more convictions overturned, bringing to 50 the number that have been thrown out as a result of Mr. Perez's statements. Though no officers have yet been criminally charged, the police department has filed administrative charges against 10 officers implicated in the scandal.

In recent weeks, Chief Bernard Parks of the police and District Attorney Gil Garcetti have warred openly about the course of the investigation, with Mr. Garcetti saying the police department refused to provide him with necessary information and the chief saying Mr. Garcetti manufactured the controversy over the information for political gain.

Despite a rebuke of Mr. Parks by the Police Commission and assurances from both parties that they would work together, the two officials feuded as recently as last week over whether to grant officers immunity from administrative discipline for failing to come forward sooner if they would agree to do so now.

Councilwoman Cindy Miscikowski, who co-sponsored the request approved today by the council, has expressed growing uneasiness with the potential for conflicts of interest with agencies from the local to the federal level investigating themselves. The district attorney's office has been reported to have ignored early warnings about the credibility of Officer Perez, and in at least one case declined to prosecute an officer fired after he was accused of beating a gang member. And news reports have raised questions about F.B.I. and Immigration Service involvement with Rampart officers.

The request for outside intervention is considered evidence of city officials' dismay over the behavior of their top law enforcement officials.

Mike Feuer, another sponsor of the request, said he felt the criminal inquiry had been imperiled by infighting. "I think it's come down to this: We can continue to allow the investigation and the prosecution arising from Rampart to be undermined by the finger-pointing and the backbiting or we can try to adopt a different approach," Mr. Feuer said.

Bill Advances For Financing Of Campaigns By the Public

By PAUL ZIELBAUER

HARTFORD, April 5 — A bill forged by state Democrats to provide public money for state political campaigns and establish voluntary limits on the amount candidates for those offices should spend was narrowly approved by Connecticut's House of Representatives tonight.

The bill, if it survives a vote in the State Senate and the scrutiny of Gov. John G. Rowland, whose fellow Republicans in the House denounced the measure today as a sham, would put Connecticut among a select group of states that give public money to candidates to reduce the influence of special interest groups.

Like existing laws in states like Nebraska and Maine, Connecticut's bill does not mandate spending limits for political campaigns, but only suggests voluntary limits, beginning in 2002. Though candidates would be free to flout the suggested spending caps — which range from $50,000 for state House races to $6 million for a candidates on a gubernatorial ticket — the bill's Democratic supporters said public pressure to stay within those limits would be enormous.

"I think you'd have a lot of explaining to do if you went beyond the caps," said David B. Pudlin, the Democrats' majority leader in the House.

Republicans vociferously urged the bill's defeat, saying it would limit political expression and unfairly hurt their candidates for office. But after nearly five hours of debate, the measure passed by a vote of 77 to 72, largely along party lines.

"The spending limits in this bill are patently unfair," said Robert M. Ward, the Republican House minority leader, ticking off a Top 10 list of reasons why the bill should be rejected. "I can't help think when I look at it that it's meant to pick on Republican candidates."

Today's campaign finance bill represents a compromise between House and Senate Democrats who in recent weeks achieved common ground over the issue after each had proposed separate, and very different, campaign finance proposals earlier this year.

It would create voluntary limits on campaigns for almost all state elective offices, including the joint ticket for governor and lieutenant governor, attorney general, secretary of state and all 151 seats in the General Assembly, starting in 2002.

Beginning in 2006, each gubernatorial ticket could spend up to $6 million for a primary and general election race, $5.5 million of which would come from publicly raised funds. In races for the state's constitutional offices like attorney general, secretary of state, treasurer and comptroller, candidates could spend up to $1,325,000, most of which would also come from a state grant.

Campaigns for seats in the legislature would not receive any public money, but House candidates would face a voluntary spending cap of $50,000, and Senate candidates would be under a $130,000 cap.

Candidates who disregarded the spending limits would not get public funds. Candidates who exceeded the limit after taking public money would have to repay the full amount or face larceny charges.

To discourage candidates from exceeding the voluntary spending limits, the bill includes a provision that would give complying candidates a grant equal to the amount of money their opponents spent beyond the cap. For example, if a House candidate spent $10,000 more than the cap, the state would give the opponent $10,000.

To help pay for the state's most expensive races, the bill would create a Citizens' Election Fund, financed largely by voluntary donations from individual and corporate taxpayers. The bill would cost the state $3 million to $9.5 million a year in lost tax revenue, said Representative Alex Knopp, the Democrats' main defender of the bill on the House floor today.

The bill's passage, though by a slim margin, reflected the enduring legacy of a scandal in which the former state treasurer, Paul J. Silvester, pleaded guilty last September to federal corruption and money laundering charges. Since that plea, Mr. Silvester's fellow Republicans have been forced to seem open to almost all kinds of campaign finance reforms, and Democrats have hammered them on the issue.

"That showed that you can't just rely all the time on piecemeal reform," Mr. Knopp said today in the House, as he waved a copy of Mr. Silvester's federal indictment during a speech. "By adopting this amendment today, it's a very important response to the scandal of Paul Silvester."

If approved in the Senate, where Democrats hold a tenuous 19-to-17 majority, the bill would go to Governor Rowland, who has said he will not favor any campaign finance measure that does not have bipartisan support.

Q + Heart Disease

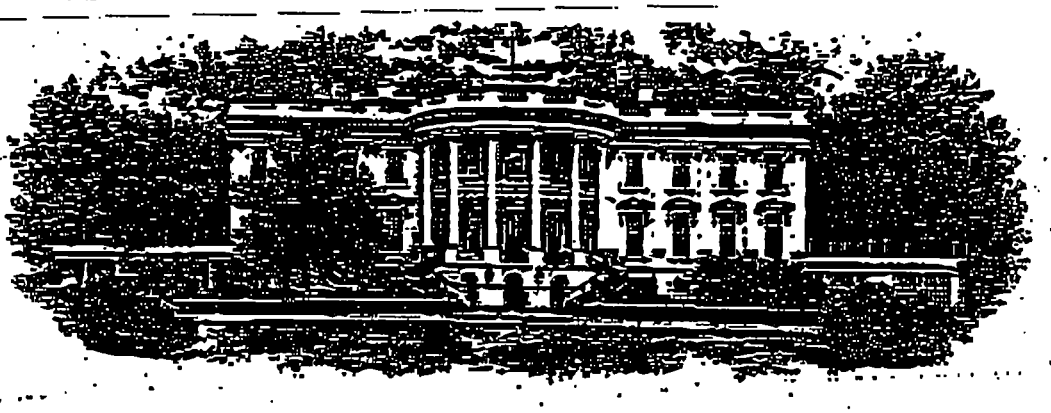
4/11 Barbara Woolley · 6-2930

Hillary Q + Heart something
dates in July - and if not, when? July 10th = 21st

Dr. L'Enfant - NHLBI - learned concept of
Task Force - like BC Action Plan

Need Task Force addressing . . .

NHLBI -
but also include other appropriate at HHS.
CDC, Q's Office



The White House
Office of Public Liaison

Barbara Woolley
Special Assistant to the President
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Number of Pages (Including cover): _____

Date: 4-12-00

To: Heather Howard

Fax Number: 62878

Office Number: _____

Comments: Women / Heart

womenheart the national coalition for women with heart disease

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www.womenheart.org

April 6, 2000

Ms. Barbara Woolley
Special Assistant to the President
Office of Public Liaison
The White House
OEOB – Room 118
1600 Pennsylvania Avenue, NW
Washington, DC 20502

Dear Barbara:

Thank you so much for meeting with our WomenHeart delegation Tuesday morning. Representing the largest patient constituency in the nation, we were pleased to bring the problem of chronic undertreatment of women with heart disease to your attention. This disease affects 8,000,000 American women and 500,000 die from it each year, many of them prematurely and entirely preventable. This is a shameful waste of women's lives and completely unacceptable.

We are very excited to work with you and Lauren Supina to schedule a White House event focusing the nation's attention on women and heart disease. We continue to work with Dr. Lenfant at NHLBI to develop his national task force concept, and attach for your information our follow-up letter to him that describes our meeting with you.

Thank you again for your kind hospitality and interest in our efforts. Enclosed are our Fact Sheet, directories of our Advisory Board and Corporate Advisory Committee, and additional copies of our new brochure for your colleagues. I will call your office next week to schedule a time for us to talk.

Sincerely,

Nancy Loving
Executive Director

Enclosures

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DELIVERED BY FAX
April 5, 2000

Dr. Claude Lenfant
Director, NHLBI

Dear Dr. Lenfant:

We officially launched WomenHeart Monday at a wonderful kick off luncheon, during which we inaugurated and presented our first Wenger Awards named to honor Nanette Wenger, who was very surprised to say the least! (see attached press release for a list of the winners). Attending the luncheon were Sara Kovner, Special Assistant to Secretary Shalala, Dr. Wanda Jones and the staff from HHS's Office on Women's Health, representatives from AHA and ACC, women's health advocates, and women with heart disease, as well as our Advisory Board and representatives from our 14 corporate sponsor companies.

On Tuesday morning, a group of 25 of us met at the OEOB with Lauren Supina, Assistant to the President and Director of the Women's Issues Office, and Barbara Wooley, Special Assistant to the President in the Office of Public Liaison. We told them of our desire to work in partnership with NHLBI, ACC and AHA, and of your interest in convening a national task force addressing the chronic undertreatment of women with heart disease. They thought the task force launch could make a great White House event and even feature the President, First Lady or the Gores. They also thought the task force could include representatives from other entities within HHS, particularly CDC and the Office on Women's Health, and might even become a Secretary's initiative.

I will soon call your office to schedule a time for us to discuss these developments next week. Thank you again for your interest in our efforts and commitment to improving women's health. I may be reached most directly at my office telephone, 301-493-9513.

Sincerely,

Nancy Loving
Executive Director

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FOR IMMEDIATE RELEASE
March 31, 2000

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Women Heart Patients to Launch National Organization, Present Awards for Excellence on April 3rd

Provides Web Site and Support, Education & Advocacy for 8,000,000 American Women with Heart Disease

Washington, DC – A group of women living with heart disease will launch a new national organization on Monday, April 3rd, titled, WomenHeart: the National Coalition for Women with Heart Disease, at a noon kick-off luncheon at the JW Marriott Hotel. It is also launching its Web site, www.womenheart.org, that features information, chat rooms and bulletin boards.

WomenHeart will also present six awards for excellence, named the Wenger Awards in honor of the world famous cardiologist, Dr. Nanette Kass Wenger, Professor of Medicine at Emory University School of Medicine and Chief of Cardiology at Grady Memorial Hospital in Atlanta. The Year 2000 Wenger Award winners are as follows:

Advocacy:	Phyllis Greenberger, Society for Women's Health Research
Communications:	Kathleen McAuliffe, *MORE Magazine*
Community Education:	National Black Women's Health Project
Corporate Leadership:	DuPont Pharmaceuticals Company
Healthcare:	Debra Judelson, M.D., American Medical Women's Association
Public Policy:	National Coalition FOR Women Against Tobacco

"Since heart disease kills half of all American women, this organization is long overdue," said WomenHeart executive director Nancy Loving, who had a heart attack at age 48. "For too long women with heart disease have been undertreated, invisible and isolated. WomenHeart will give us a seat at the policy table and push women's heart disease to the top of America's healthcare agenda."

For more information about WomenHeart, see the **About Us** section of its Web Site. Its stellar Advisory Board, which will be meeting at the JW Marriott Hotel on April 3rd, is composed of leading women cardiologists, health care professionals and women's health advocates. WomenHeart has been granted 501(c) (3) non-profit status from the IRS. # # #