OUR MISSION

Founded in 1999 as the National Center for Policy Research for Women & Families, we are now the National Research Center for Women & Families. Our mission stays the same: to make research-based information a valuable tool for improving the lives of women, children, and families every day.

Our Center is a unique blend of research and advocacy. We focus on the health and safety of women, children, and families. We gather, synthesize, and use medical and scientific expertise to improve programs and policies that affect people’s lives. We scrutinize research findings, conduct research ourselves, and mold that information to be useful and interesting to the public, the media, opinion leaders, and policymakers. We are dedicated to making a difference for adults and children across the country.
Two thousand and three was an important year for the National Center for Policy Research for Women & Families, including the decision to shorten our name to something easier to say and remember. Beyond that, we made substantive and substantial advances in improving the health and safety of women, children, and families, using research information that has implications for our daily lives.

It is amazing but true: our mission is unique. Ours is the only national organization that has set out to make this kind of research-based health and safety information understandable and useful to families across the country.

We are an essential voice because sound science and accurate information can help us in ways large and small. Unfortunately, spin and sound bites tend to shape social policies and programs. Experts with a financial stake in the outcomes dominate public and political attention so thoroughly that more objective voices and sources of information can be lost.

When that happens, the interests and needs of ordinary women and their families rarely become part of the discussion. Consequently, programs and policies that could help improve their health and safety do not get the support they deserve—and women, children, and families suffer. Our singular mission is to serve as that missing, objective voice. As a research-based center, we provide information based on facts, not ideology. We are non-profit as well as non-partisan. We have no financial stake in the programs or policies we analyze. We rely on scientific expertise provided by our highly qualified staff and our nationwide network of unbiased, well-respected researchers.

Since its founding, our Center has become a strong, objective, and highly sought-after voice of reason, a trusted source of sound science and useful information for a broad audience. Policy-makers and policy analysts are one target for our findings, through briefings, hearings, meetings, conferences, and written materials. To fulfill our mission, we also want to inform those who most need the information yet most often have scant access to the facts. Therefore, we translate complex research findings to make them usable and interesting. Then we work with the media to help “get the word out” in order to help shape the public debate, while also providing our work directly to the public—free of charge—through our Web site, articles, publications, speeches, and TV and radio interviews. An enterprise that strongly values collaboration, we share our publications and information with other organizations, researchers, and advocates. We coordinate and work with them to inform the public and to become a meaningful part of the public debate on policy issues.

Our work has made a difference, protecting adults and children from dangerous medical products, warning pregnant women to avoid risky food and chemicals, and improving legislation that affects people’s lives every day. It would not have been possible without the wonderful support and encouragement of our Board of Directors, our National Advisory Board, our talented staff, our partners from other organizations, and the generosity of individuals, organizations, and foundations. Thanks to our supporters, we continue to be a trustworthy source of information as well as an effective advocate for the health and safety of adults and children.

Diana Zuckerman, Ph.D.

1 Although our name was not changed until 2004, this annual report uses our new name, the National Research Center for Women & Families.
During 2003, the Center continued ongoing programs to improve medical care for women with breast cancer, warn families about the risks of dangerous chemicals and medical products, help children exposed to domestic violence, and meet the needs of blind adults and children. We also launched projects to decrease smoking among girls and women, and to reduce chemical exposures that can harm pregnant women and children. Here are highlights from a busy year.

‘Breast Cancer Patients Have Choices’ Public Education Project

Each year, more than 150,000 women in the United States are diagnosed with early-stage breast cancer. Experts agree that for most cases of early-stage breast cancer, lumpectomy with radiation is just as safe and effective as mastectomy. Nevertheless, almost half the women eligible for lumpectomy undergo mastectomy. Many women are not even told that lumpectomy with radiation is an equally safe option. Women without insurance, with lower income or education, living in certain regions of the country, with older doctors, or using community hospitals are especially likely to undergo mastectomies, even when they are eligible for less radical surgeries.

During 2003, the Center continued its public education efforts to ensure that all breast cancer patients have the most accurate and understandable information about their treatment options. This project began in December 2001 with a national, one-day working conference on early-stage breast cancer, Using Research to Inform Patients of Breast Cancer Surgery Options, at the National Institutes of Health (NIH). The conference brought together nationally respected health practitioners, medical researchers, and patient advocacy groups to develop strategies to ensure that women newly diagnosed with early-stage breast cancer are accurately informed about their options for surgery and related treatments.

In September 2003, we organized a smaller, one-day working meeting on stage zero breast cancer, lumpectomy with radiation is just as safe and effective as mastectomy. Nevertheless, almost half the women eligible for lumpectomy undergo mastectomy. Many women are not even told that lumpectomy with radiation is an equally safe option. Women without insurance, with lower income or education, living in certain regions of the country, with older doctors, or using community hospitals are especially likely to undergo mastectomies, even when they are eligible for less radical surgeries.

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By focusing on how research information could be used to help patients make treatment decisions, the meetings were an important first step in our public education efforts for these widely misunderstood conditions. Experts in the field recognized the importance of these precedent-setting meetings, made possible by funding from numerous agencies of the U.S. Department of Health and Human Services (HHS) – the National Cancer Institute (NCI), the NIH Office of Research on Women’s Health, the HHS Office on Women’s Health, the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention, the Health Research and Services Administration, and the Center for Medicare and Medicaid Services.
The September 2003 meeting was funded by a contract from the HHS Office on Women’s Health (OWH) with additional support from the NCI and the NIH Office of Research on Women’s Health (ORWH). The Center used the success of these meetings to launch a public education campaign entitled “Breast Cancer Patients Have Choices.” Since many patients are not aware of all treatment options and don’t realize that mastectomy is not necessary for every patient, the Center has worked in partnership with NCI, OWH, AHRQ, and ORWH to develop a booklet on surgical options for early-stage breast cancer patients. The booklet will be provided free to women and their families. The goal is simple: to make certain that all patients—regardless of income, education, where they live, what language they speak, or where they receive treatment—have the information they need to make informed choices.

Blind Adults and Children
It is surprising how little we have known about blind adults and children in the United States, since about one million legally blind Americans live in cities and towns across the country. The public and policymakers are aware of some of the challenges blind individuals face, but they are not knowledgeable about their daily lives and whether they have the services they need to be productive, self-sufficient, and happy.

At several national conferences in 2003, we presented findings from our landmark national study of men and women who are legally blind, a study that started in 2000. The data came from the one and only national survey on the subject, conducted by the Centers for Disease Control and Prevention. No one had analyzed those data to examine the daily lives of men and women who are legally blind. A contract from Guide Dogs for the Blind and The Seeing Eye enabled our Center to statistically analyze the data for the first time and to share the information with these two nonprofit organizations. Thanks to a generous grant from the Aid Association of the Blind of the District of Columbia, we analyzed the national implications of the findings. A report intended for the general public, advocates for blind adults, and policymakers covers the health and policy implications. Our study found that Americans who are blind are a very diverse group—all ages, races, and ethnic groups; affluent and poor; high school dropout and lawyer; urban and rural; married and single; healthy and in poor health. Most blind adults in the United States, however, have one thing in common: They were not born blind. Rather, most lost their vision due to disease as they aged and have had to adjust to losing their vision in order to maintain independent lives. This has serious public health implications, which we discuss in a report completed and released in 2004. Our study and report are timely because, as baby boomers age and people live longer than ever before, the number of adults with vision impairments will increase dramatically. The escalating prevalence of obesity also is worrisome because of the link to diabetes, which can result in vision loss. These factors combine to make blindness a pressing public health concern.
Safety of Medical Products

Industry spends billions to advertise and promote new prescription drugs and medical devices every year. Promotional activities are very effective in persuading doctors to prescribe products for their patients, but the data regarding these products' safety and effectiveness for certain types of patients are sometimes complicated, confusing, unclear, or unknown.

The Center scrutinizes the policies and procedures used to regulate and advertise medical products, examining as well the data for selected products when questions arise about their safety or effectiveness. Our goal is to make sure that all medical products are safe and effective and to persuade the media to provide more balanced information to the public. To fulfill this goal, the Center regularly testifies before the Food and Drug Administration (FDA) and U.S. Congress, works with consumer and patient organizations, and talks with government officials and the media. Our Web site, media presence, and Online Health Hotline are major sources of information, often providing important warnings years before such information becomes widely available to consumers.

In 2003, the Center was a highly visible source of information about safety research on several medical products, including silicone gel breast implants, as the FDA considered whether to approve these products for the first time. Prior to the FDA’s public Advisory Committee meeting in October 2003, the Center conducted a training workshop and provided useful information about the role of the FDA for women who wanted to testify about their personal experiences or on behalf of nonprofit organizations. We trained them to understand the lack of long-term safety information about a specific product and the specific medical problems they had experienced, which enabled them to testify effectively in the short period allotted to them. In addition, the Center arranged for volunteers to read the testimony of implant patients who were too ill to travel or could not afford to come to the hearing.

The Center’s president, Dr. Diana Zuckerman, the last public witness to testify at the hearing, focused on the need for long-term safety data. As a result of the testimony of Center staff and many other individuals and organizations, the FDA agreed that the data for long-term safety were insufficient to approve silicone gel breast implants.

Also in 2003, the Center participated in a national working group convened by HHS to discuss the risks and benefits of hormone therapy for menopause. The working group’s purpose was to develop easy-to-understand messages and fact sheets for women across the country. The result was a public education campaign aimed at ensuring that all women can make informed choices about whether hormone therapy is right for them. As a member of the working group, we shared in the FDA Commissioner’s Special Citation for our work, awarded in 2004.

Center staff also testified before FDA advisory panels about the safety of several types of facial injections, including Artefill, Restylane and Hylaform. In all our testimony, we expressed concerns about the small number of women studied, the lack of racial diversity in the women studied, and the lack of convincing proof that the products were as safe or effective as the companies claimed.

We also worked with the Congressional Black Caucus and the National Medical Association to urge the FDA to require that medical products be studied on all racial minorities, to ensure that the products are safe and effective for all Americans, not only whites.
Environment and Health

The past decade has seen increasing concern about environmental chemicals and toxins that could harm human health. Thousands of chemicals are introduced into the environment with relatively little data about their safety, especially for young children and prenatal exposures. In addition to the well-known concerns about cancer-causing chemicals, scientists are pointing out the need to study exposures that can cause developmental delays, such as lead and mercury, and chemicals with hormonal effects that can cause early puberty and reproductive abnormalities in children and cancer in later years.

Our focus turned in 2003 to warning women and families about the dangers of mercury in tuna and other fish. Dissatisfied with the government’s advisory to pregnant and nursing women and young children, we produced an Issue Brief, “Methylmercury in Fish: The Facts.” It clearly explains why mercury is harmful, which fish are high in mercury, specific concerns for tuna, and guidelines for how much and what kinds of fish certain people can eat. The Environmental Protection Agency (EPA) Web site recommends our Issue Brief, making it an important source of information for families and policy experts across the country. As part of our efforts to protect consumers, the Center has repeatedly urged the FDA to include warnings about mercury in tuna in the national advisory for pregnant and nursing women and small children.

In December 2003, Dr. Zuckerman testified about the need to warn the public about mercury in tuna at a joint public meeting of advisory committees to the FDA and the EPA. A few days later, the National Environmental Trust invited her to speak at its press conference on this issue at the National Press Club.

The Center also became involved in EPA meetings on the safety of PFOA, a key ingredient in the manufacture of non-stick cookware, stain-resistant clothing and carpeting, and some medical sutures. The EPA is concerned about possible health risks of the chemicals in the industrial sites where the products are made. The Center testified about those risks and the possibly harmful effects from PFOA in the home. Further, we participated in working groups with representatives from chemical companies, health departments, and consumer groups to ensure that the EPA is examining the risks of these exposures.

Smoking Among Women and Girls

Smoking is the major cause of preventable deaths among women. The Women’s Movement has struggled to achieve equal rights for women, but the equality women have achieved in smoking and tobacco-related mortality is not what women’s advocates had in mind. Since 1950, women’s death rates for lung cancer, a disease primarily attributed to smoking, has increased 600 percent. In addition to lung cancer, women who smoke are also at greater risk for heart disease; stroke; cancers of the bladder, liver, pancreas, and kidney; gastric ulcers; and a variety of reproductive problems including miscarriage and infertility. Smoking has also been linked to stillbirths and sudden infant death syndrome.

Smoking is on the rise among young girls and may be especially increasing among girls who see themselves as non-traditional, independent, and iconoclastic. Most women’s organizations have not been actively working to decrease tobacco use, partly because smoking was not perceived to be a women’s problem, and partly because smoking was seen as a decision made by the smoker and therefore her own responsibility. Meanwhile, advertising and the promotion of sports events by tobacco companies have fostered a positive image of tobacco and of girls and women who
smoke. Recent research suggests that those images are often more powerful than knowledge of health risks when children are deciding whether to smoke. Today’s average 14-year-old already has been exposed to more than $20 billion in imagery advertising and promotions since the age of 6, creating an environment in which smoking appears to be glamorous, social, and normal.

The Center’s anti-smoking initiative, Women Speaking Out on Smoking, began in 2003 with generous funding from the American Legacy Foundation. The project is designed to generate and coordinate anti-tobacco information and advocacy among national women’s and girls’ organizations. To kick off our efforts, we put on two luncheons on the topic, attended by women leaders and interns from a wide range of organizations. This report’s Community Outreach section describes the luncheons.

As a member of the Campaign for Tobacco Free Kids, the Center continues to work with a coalition of other health organizations, such as the American Cancer Society and the American Lung Association, to prevent children from smoking. The staff has been active in the coalition’s effort to gain federal legislation mandating FDA oversight of tobacco.

**Work and Family**

Millions of American women balance work and family, but unpredictable school schedules, uncertainties about day care, responsibilities of caring for a sick or disabled family member, and a host of other challenges make for an increasingly stressful juggling act. To help alleviate that stress, the Center works with experts from across the country to help ensure that families get the information, programs, and policies they need.

Center staff were especially visible in the media, explaining the latest findings on childcare on several national TV news programs. Those findings were complex and easily misinterpreted: new research indicated that children’s development improves if the quality of their relationship with their mother is better, if childcare is higher quality, if the mother is not employed full time when the child is a toddler, and if income is higher. Since mothers who work more hours can often afford better quality day care, mothers’ full-time jobs can have both a positive and a negative impact on their young children.

In addition to working closely with the national media to improve the accuracy of their coverage of research on childcare and working parents, the Center also provides information about the latest research on our Web site, www.center4policy.org.

In September 2003, we hosted an informal Fourth Fridays luncheon presentation by one of the foremost experts in the field, Jeanne Brooks-Gunn, a professor at Columbia University. The lunch was well attended by women leaders and policy analysts from the Washington metropolitan area, as well as pregnant women and young mothers. We disseminated information from the luncheon in our Voice for Women & Families newsletter.
Fourth Fridays Luncheon Series
On the fourth Friday of most months, the Center hosts a luncheon devoted to a different timely health topic. We invite policy experts and researchers to provide accurate and useful information on current and controversial health issues. Between 35 and 55 people attend each Fourth Fridays Luncheon.

Free and open to the public, our luncheons convene in a conference room at the Washington law offices of Reed Smith. That firm donates use of the conference room, beverages and dessert; sponsors including Corner Bakery, Baja Fresh, Fresh Fields/Whole Foods, Potbelly Sandwich Works, and Preferred Office Club donate the salads and sandwiches. Topics and speakers for 2003 were the following:

✪ “Watching Our Weight: What We Need To Know,” January 24. Guest speakers were Sally Squires, staff reporter, The Washington Post health section, author of the Lean Plate Club column; and Wayne Miller, Ph.D., professor of exercise science and nutrition, George Washington University.

✪ “Women’s Health Policy Challenges in 2003,” March 28. Guest speakers were Leslie Wolfe, President, Center for Women Policy Studies; and Aaron Spork, legislative assistant for Congresswoman Shelly Moore Capito (R-W.Va.).

✪ “The Fountain of Youth and Seeking Physical Perfection: Body Sculpting, Cosmetic Procedures, and Health,” April 25. The guest speaker was Audrey Sheppard, former Director, FDA Office of Women’s Health.

✪ “Does It Work? Loopholes and Safeguards for Natural Supplements,” June 27. The guest speaker was Lesley Fair, senior attorney, Bureau of Consumer Protection, Federal Trade Commission.

✪ “Bottled Water and Water Filters: Hype or Healthy,” July 25. Guest speakers were Ronnie Sandroff, health editor, Consumer Reports; and Eric Olson, senior attorney, Natural Resources Defense Council.

✪ “Child Care and Working Mothers,” Sept. 19. The guest speaker was Dr. Brooks-Gunn, Columbia University.

✪ “How Tobacco Companies Target Girls and Women and What We Can Do About It,” December 3. Guest speakers were Karen Johnson from NOW; Karen Martin from the American Legacy Foundation; Kim Goodman from the Mautner Project; Nina Chaudhry from National Women’s Law Center; and Laurie Westley from Girl Scouts of the USA.

Summer Intern Lunch
In July, the Center organized a very well-attended and enthusiastic luncheon workshop for summer interns from across the country who were working at Washington-area organizations. Guest speakers at the workshop, at Reed Smith’s conference facility, were Lesley Fair of the Federal Trade Commission and
COMMUNITY OUTREACH AND EDUCATION

Kimberly Weich Reusché, manager of constituency relations, Campaign for Tobacco Free Kids. Sixty-five interns attended.

Web Site
Because we are an organization dedicated to providing free information to the public, our Web site (www.center4policy.org) plays a key role in the Center’s community outreach and education efforts. Our Web site includes four major sections: Women’s Health; Children and Teens; Work, Family, Disabilities, and Economic Security; and What’s New.

The first three focus on translating research-based information to make it interesting and easy for the widest possible readership, while also including footnoted documents for researchers, policy analysts, policymakers, and scholars. The Women’s Health section includes information on a wide range of issues, such as breast cancer, cosmetic surgery, hormone therapy, dietary supplements, weight control, and violence. The Children and Teens section includes a wide range of information on children’s health and mental health issues; risky behaviors such as alcohol and drug use and sexual activity; and violence in dating, in the home, and in the community. The Work, Family, Disabilities, and Economic Security section includes articles on juggling work and family, information from our study of blind adults and children, and articles on welfare and Social Security. The What’s New section includes newsletters and other information, and provides advice on how to contact members of Congress to express one’s views on health and safety policy issues.

In addition to our main Web site, we have a site designed especially for breast cancer patients interested in breast reconstruction and for teens and young women interested in breast augmentation. In 2003, we completely redesigned that site, www.breastimplantinfo.org. The new format provides clearer and more concise information to women who want information about breast reconstruction and augmentation. This Web site has registered a large increase in traffic.

The Center continued its Online Health Hotline which was managed by Liz Nagelin-Anderson, MS, and subsequently by Elizabeth Santoro, RN, MPH. The hotline continues to be very popular, and staff answer e-mails every week from women with health problems or questions about medical research findings.

Speeches and Presentations at Meetings and Conferences
In addition to our luncheon series, Center staff members were invited speakers at national meetings and scientific conferences. Here are representative examples:

✪ Dr. Zuckerman presented at the annual Art and Science of Health Promotion conference in February. Her talk was part of the panel on Realizing Visions in Health Promotion.

✪ Dr. Zuckerman presented a talk on “Breast Cancer and New Policy Directions for Preventing Cancer” at the National Council of Women’s Organizations’ Capitol Hill briefing on women’s health issues, U.S. Senate, May 9.

✪ Dr. Zuckerman was a featured speaker at the Clearinghouse for Women’s Issues monthly luncheon in Washington on June 24. The event focused on the new budget proposals and how programs for women, children, and families would be affected.

✪ Dr. Zuckerman and Public Policy Fellow Liz Nagelin-Anderson were invited speakers at the annual national NOW conference in Alexandria, Va. in July. They spoke about the safety of breast reconstruction for mastectomy patients.

✪ Dr. Zuckerman was an invited speaker on women’s health issues at the annual conference of the New York Federation of Nurses in Manhattan in November.

Congressional Briefings and Testimony Before Federal Agencies
Whether advocating consumer-friendly medical device legislation, improvements in health care, or preserving safety net programs for women and families,
the Center has been active on Capitol Hill. We educate policymakers and their staffs about targeted issues as well as advocate for federal policies that are based on objective scientific research rather than on partisan politics. During 2003, elected officials continued to look to the Center for research information, and the news media regularly called upon the Center for unbiased commentary on policy issues.

On December 5, Dr. Zuckerman spoke about children and poverty at a briefing in the House of Representatives. Entitled “No Child Left Behind?: Children, Poverty and Policy,” the briefing was convened by the Population Resource Center.

The Center provided information about research findings and consumer needs on a range of health issues by testifying at public meetings of federal agencies such as the FDA and EPA. Here are a few examples:


- Dr. Zuckerman presented a talk entitled “Blind Adults in America: Their Lives and Challenges” at the Twelfth Annual Program Managers Conference for Independent Living Services for Older Individuals, sponsored by the U.S. Department of Education, April 2.

- Dr. Zuckerman and Public Health Fellows Elizabeth Santoro, RN, and Jill Follows, RN, JD, presented public comments at the FDA General and Plastic Surgery Devices Advisory Panel meeting on the safety of silicone implants in Gaithersburg, Md., October 14-15.

- Ms. Follows, Senior Public Health Fellow, testified at the FDA General and Plastic Surgery Devices Advisory Panel meeting on Restylane and Hylaform, November 21.

- Dr. Zuckerman presented public comments at the FDA Food Advisory committee meeting on methylmercury in fish on December 10. In July 2002, she had been an invited speaker to the same advisory committee.

**Events**

The Center’s annual media luncheon briefing took place at the Harvard Club in New York City on May 28. We covered three topics: the safety of natural supplements; the safety of plastic surgery and injectables; and the safety of medical implants, including breast implants. Guest speakers were Lesley Fair, senior attorney, Bureau of Consumer Protection, Federal Trade Commission, and Dr. Rosaly Correa, director, Office of Women’s Health, Agency for Healthcare Research and Quality. Journalists from national women’s magazines and other national news media attended this event. Those outlets included *Glamour, Self, Allure, Women’s Day, Family Circle, Seventeen, Lifetime Television*, *Today Show*, and *Time* magazine.

The Center also conducted lunch briefings for the media in October to coincide with the FDA Advisory Committee meeting on silicone breast implants in Gaithersburg, Md.

**In the News**

As a result of our press events and as testament to the Center’s growing...
reputation as a source of reliable information, the number of requests for interviews and information increased substantially throughout the year, giving the Center a strong media presence. In addition, op-eds and letters to the editor from Center staff were published widely throughout the country.

For example, Dr. Zuckerman appeared on the Today Show, NewsHour with Jim Lehrer, CNN American Morning, CNN Live Today, NBC News, ABC News, ABC News 7 (Washington, D.C.), CNBC, Fox News Dayside with Linda Vester, and Fox News From the Heartland. She also gave interviews to numerous radio networks and local programs.

FINANCIALS: STATEMENT OF FINANCIAL POSITION

Year Ended December 31, 2003

ASSETS

Current assets
- Cash and cash equivalents: 194,820
- Accounts receivable: 185,653
- Prepaid expenses: 2,537
- Total current assets: 383,010

Property and equipment
- Furniture and equipment: 5,680
- Less: depreciation: -5,504
- Other assets
  - Deposits: 1,665
- Total current assets: $384,851

LIABILITIES

Current liabilities
- Accounts payable and accrued expenses: 23,432
- Total current liabilities: 23,432

NET ASSETS

- Unrestricted: 269,645
- Temporarily restricted: 91,774
- Total liabilities and net assets: $384,851

EXPENSES TOTAL
- RENT: 5%
- Foundation Grants: 77%
- Individual Contributions: 5%
- Rental Income: 12%
- Program Services: 98%
- Fundraising: 1.3%
- Administration: 0.7%

REVENUE TOTAL
- 77%
- 12%
- 5%
- 1%
- 1%
- 0.7%
- 1.3%
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