



THE VOICE

for Women & Families

GROUNDBREAKING REPORT RELEASED AT HILL BRIEFING

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What is it like to be legally blind in the United States? Our Center discovered a shocking lack of data and decided to fill the void.

We conducted the first study ever on a representative sample of all adults who are legally blind in the U.S. With the support of the Aid Association for the Blind of the District of Columbia, we released our report in a place where it could do the most good: Capitol Hill. In February, Low Vision Awareness Month, we held a congressional briefing on the report in cooperation with the Congressional Vision Caucus and the Congressional Caucus on Women's Issues.

Dr. Margaret Giannini, Director of the Office on Disability at the U.S. Department of Health and Human Services, made a forceful introduction to our Congressional briefing, saying, "We cannot build a research and policy agenda to address a need unless we understand fully what that need is. We need a roadmap, and now, finally, thanks to the National Center for Policy Research for Women & Families, we have one."

The policy implications are very important. As baby boomers age and people live longer than ever before, the number of adults who are legally blind or have other visual impairments will increase

"We cannot build a research and policy agenda to address a need unless we understand fully what that need is. We need a roadmap, and now, finally, thanks to the National Center for Policy Research for Women & Families, we have one."

-- Dr. Margaret Giannini, Director of the Office on Disability at the U.S. Department of Health and Human Services

The National Center for Policy Research (CPR) for Women & Families uses research-based information to promote the health and well-being of women, children and families.

There are about one million legally blind Americans living in U.S. households, not including those in nursing homes and other institutional facilities. Americans who are blind are found in every demographic -- affluent or poor; high school drop out or lawyer; every ethnic group; urban or rural; married or single.

Most adults with visual impairments have one thing in common: They were not born blind. Most lost their vision due to diseases as they got older, and their average age is 62. They have had to relearn many activities in order to continue to live independent lives.

dramatically. Obesity is causing an epidemic of diabetes, which can result in vision loss. These factors combine to make blindness a pressing public health concern.

Representatives Gene Green (D-TX) and Ileana Ros-Lehtinen (R-FL), co-chairs of the Congressional Vision Caucus, thanked us for our report and spoke at the briefing.

"We need to work to ensure that adequate resources are directed toward the research, prevention, and treatment of eye disease," Rep. Green reminded the audience of advocates and policy

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Graphic design contributed by neo design. 

SMOKING: A WOMEN'S ISSUE?

Everyone knows that smoking is bad for your health. But did you know that smoking is uniquely harmful to women?

Why Worry Now?

Smoke-free shopping malls, restaurants, and entertainment centers are booming. States such as California and New York have adopted policies to combat second-hand smoke.

Unfortunately, even with many well-crafted programs and policies nationwide, the number of women and girls who smoke remains high -- and the number of women dying from smoking-related diseases is on the rise.

Girls and Smoking

Tobacco companies have invested millions in their attempt to persuade girls that smoking will make them sexy, fun, and independent. The advertising boom for "women's" cigarettes in the late 1960's and early 1970's coincided with sharp increases in the number of teenage girls taking on the habit. From 1967 to 1973, when sales of women's cigarettes increased, smoking rates more than doubled among 12-year-old girls. Smoking is a habit that almost always begins in youth -- usually before age 16. If a teenager graduates from high school without ever smoking regularly, he or she probably never will.

Not only do teenage girls want to look independent and glamorous, they also may smoke in an effort to lose weight. Cigarette advertising subtly equates smoking with slimness, and the tactic helps convince girls that smoking is a strategy to have the body they have always wanted.

Women and Smoking

Almost 22 percent of all American adult women (20.7 million) are smokers. Although they are slightly less likely to smoke than men, the gender gap in smoking is decreasing every year, and

the results are deadly. Lung cancer is the leading cause of cancer deaths among women in the United States, but smoking also increases the risk of breast cancer, blindness, and stroke. Smoking in adolescence is linked to anxiety and depression in young adults. In addition, there is some evidence that women may be more easily addicted to nicotine than men.

Smoking and Pregnancy

The other reason why smoking is a women's issue is because of the unique risks of smoking while pregnant. Hundreds of thousands of women in the U.S. will smoke while they are pregnant this year, increasing the risk of serious health problems such as low birth weight, premature birth, and Sudden Infant Death Syndrome (SIDS). There are approximately 4,000 chemical compounds in tobacco smoke, many of which are toxic and some of which can cause cancer. The carbon monoxide from tobacco use can reduce the amount of oxygen for the developing baby, and nicotine can reduce blood flow to the uterus.

With a Circle of Friends grant from the American Legacy Foundation, we are working to energize nonprofit organizations to combat smoking among women and girls. We held a lunch gathering to feature the anti-smoking efforts of several well-known national women's and girls' organizations, including Girl Scouts of the USA, NOW, the National Women's Law Center, the Older Women's League, the Mautner Project, and our own Center. We also are reaching out to college students, encouraging them to be more active on their campuses.

We need your help to reach out to women and girls. Please contact Project Coordinator Madeleine Levin at ml@center4policy.org.

Here are just 10 of the many health benefits that start the day you stop smoking!

- #1 You are less likely to become blind.** If you stop smoking, you will be less likely to ever develop cataracts, a major cause of blindness.
- #2 You'll live longer - much longer!** Women who die of a smoking-related disease lose, on average, 14.5 years of life.
- #3 Less likely to have a stroke.** Heavy smokers (2 packs a day or more) are twice as likely to have a stroke as light smokers.
- #4 Less likely to have a heart attack.** Women who smoke are more than twice as likely as other women to have a heart attack.
- #5 Less likely to die from lung cancer.** You knew this, but did you know that lung cancer kills more women than any other cancer - and that almost 9 out of 10 of these deaths are linked to smoking?
- #6 Your spouse and your children will be less likely to die from lung cancer or heart disease.** If you think you're the only one who benefits from your quitting, think again.
- #7 Fewer wrinkles.** The Surgeon General's most recent report on smoking concludes that smokers have more facial wrinkles.
- #8 You may cheer up and relax.** You might think that smoking is relaxing, but think again. Research shows that women who smoke are more depressed and more anxious.
- #9 Save money.** Think of all the money you'll save by giving up smoking. A good strategy is to put aside the money you save every day and use it to buy something special to reward yourself for quitting.
- #10 Save your baby.** Women who want to have a baby have even more reasons to quit. Women who smoke are more likely to have a stillborn child or an infant who dies from Sudden Infant Death Syndrome (SIDS).

GROUNDBREAKING REPORT

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experts, including many professionals with visual impairments.

"It is critical that we continue to support additional research in order to be able to prevent, treat, and cure each and every incident of eye disease," emphasized Rep. Ros-Lehtinen.

Dr. Diana Zuckerman, our Center's president, presented the major findings of the report, many of which highlight previously unrecognized needs.

"This is a diverse group, but they are older and more likely to be poor than the general population. As they get older, the men still have family members to take care of them, but the women tend to outlive their husbands and other family members and end up living alone. That makes it difficult to get rehabilitation, food stamps, and other services that could help them. If we do not address the public policy concerns of blind Americans today, we could have a serious problem down the road."

"Blindness is not just something that happens to the individual. It happens to the family and to society,"

explained Jim Dickson, Vice President of Governmental Affairs for the American Association of People With Disabilities, speaking from personal and professional experience as a blind professional who has successfully advocated for better programs and policies.

The more information we have about people with visual impairments, the better we can understand what policies and services are needed to help them continue to live independent, satisfying, and productive lives. With the help of the Congressional Vision Caucus, the Congressional Caucus on Women's Issues, the Office on Disability at HHS, and advocates and researchers, we will work to make sure the information from our report is widely available and used by policy makers to improve programs and policies for adults with vision impairments.

Free copies of *Blind Adults in America: Their Lives and Challenges* are available on our website at www.center4policy.org. If you want more information, please contact Nikki Hudak at (202) 223-4000.



From right to left: Rep. Ileana Ros-Lehtinen, Rep. Gene Green, Dr. Margaret Giannini, and Dr. Diana Zuckerman on Capitol Hill discussing the policy implications of our Center's report in February 2004.

Blind Adults in America: What the Research Says

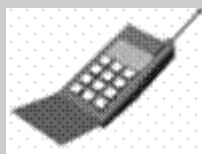
- **One in every three blind adults is over the age of 75.**
- **Most (78%) blind adults live in urban areas.**
- **Blind women are more likely to live in poverty than blind men.** While similar percentages of legally blind men and women under 65 are living in poverty (21% and 24%, respectively), after the age of 65 the gap widens, with only 8% of men living in poverty and 21% of women living in poverty. Interestingly, 21% of blind adults living in the West have a family income above \$50,000 a year, compared to 11% in the rest of the U.S.
- **Many blind adults living in poverty are not receiving welfare or food stamps.** Legally blind men in poverty are more likely to receive food stamps than legally blind women in poverty (65% to 37%) and legally blind women in poverty are more likely to be on welfare than legally blind men (24% to 12%).
- **Blind women are more likely to live alone as they age.** Only 7% of legally blind women 18-44 live alone, rising to 16% of women 45-64. By the time legally blind women are 65-74, more than one-third live alone, and over half (52%) of the legally blind women 75 and older live alone. In contrast, approximately 20% of legally blind men live alone at all ages, falling to 16% for those over 75.

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■ **In honor of our 5th anniversary you can chose up to five friends to receive our newsletter for a year for a donation of only \$25.00!**

■ Tax-deductible contributions can be sent at anytime to CPR. Use the envelope that we have attached to the newsletter to mail in a gift today.



■ You can donate your car or old cellular telephone to the Center. For more information on how to do this, please email us at info@center4policy.org or contact us by mail or telephone.

■ You can include the Center in your will or estate plans as a beneficiary. This gift will be a lasting legacy that will continue to benefit women and children for years to come.

Please call us at (202) 223-4000 with any questions you might have. Thank you again for your support. We are counting on you!

THE FDA SAYS NO TO SILICONE BREAST IMPLANTS

"I was never told of the risks. I asked the doctor if they were safe and he said 'Yes, I would not have put them in my wife if they were not safe.' "

---Judy Kemesci, breast cancer survivor, October 2003 testimony for the FDA.

The Food and Drug Administration (FDA) shocked many in January when it decided not to approve silicone gel breast implants. The agency, stating it wasn't sure that breast implants were safe, cited concerns over why breast implants break, how long they are likely to last, and what the health consequences are when silicone implants rupture and leak inside a woman's body.

These are valid questions -- and raise a bigger issue: Why have almost two million women used a medical product that the FDA has never approved? Here's what happened.

Slipping Under the Radar

Breast implants were first sold in the U.S. in the 1960's, years before the government regulated medical devices. When the FDA was given the authority to monitor the safety and efficacy of medical devices in 1976, the agency was overwhelmed with an enormous backlog of products that needed to be evaluated. Breast implants, considered a much lower priority than potentially life-saving devices such as heart valves and shunts, were allowed to remain on the market. It was expected that the FDA would require safety studies on breast implants within a few years. Instead, they stayed on the market for nearly three decades without any published clinical trials, despite many scientific concerns about safety.

Finally, in 1991, the FDA required silicone breast implant makers to submit safety studies and apply for approval. The FDA was surprised to learn that although almost one million women had breast implants in their bodies, the



photo by Alex Wong for Getty images

Erin Heimstra, Beth Nichols and Liz Santoro of our staff show photos of women who have had problems with their implants to the FDA advisory panel in October 2003.

companies had just started their clinical trials. No long-term safety studies existed. But a massive lobbying campaign by implant makers and plastic surgeons, featuring breast cancer patients, made it difficult to ban silicone breast implants.

As a compromise, the FDA restricted the sale of silicone implants, offering them to tens of thousands of women who participated in clinical trials. Most studies were of breast cancer patients or women who needed to have old or leaking implants replaced. The agency asked manufacturers to prove that silicone implants were safe before they could be sold on the open market.

Where are the Data?

This brings us to 2003, when McGhan Medical asked the FDA to review their silicone gel breast implants again. Unfortunately, the manufacturer still had not done the studies needed to prove that silicone breast implants were safe.

When a medical company applies for approval for a product, the FDA

often seeks advice from an advisory panel, composed of medical and scientific experts from universities, medical schools, and private practice. Advisory panels review the applicant's safety studies at a public meeting held by the FDA and recommend whether the FDA should approve the product.

The FDA advisory panel meeting on silicone gel breast implants was held in October 2003. At the meeting, the implant maker, McGhan (also called Inamed), described the research they conducted on their breast implants. The meeting included presentations from FDA scientists explaining where they agreed or disagreed with Inamed's interpretation of the safety studies. There were also several hours of "open public testimony" where anyone could speak about the topic. Individuals -- scientists, patients, or anyone else -- were given three minutes to testify; heads of organizations were given five minutes. Not much time to try to provide useful information to the FDA advisors!

With the help of our Center, many women's organizations were informed about the meeting and the company's research findings, and came to express their concerns about the lack of long-term data. And, 30 women from across the country were there to testify about their personal experiences -- both positive and negative.

Many of the women with implant problems had horrible stories to tell, and their testimony was often moving and frightening. The women who were happy with their implants were also persuasive, but one of them approached CPR's President, Dr. Diana Zuckerman, to ask how she could learn more about the risks of silicone gel breast implants. She looked worried and wanted more

"My left implant was ruptured, and most of the silicone had leaked out. The plastic surgeon told me there was probably silicone in my liver, lungs, and brain. I have no idea how long the implant had been ruptured. I saw no difference in how I looked."

--- Rose Rust, Silicone breast implant patient, October 2003 testimony

information. A breast cancer survivor who testified, Jesse Foreman, had lobbied Congress in favor of implants 12 years earlier at her plastic surgeon's request.

This time around, she cited her concerns about the health risks of breast implants.

What Happened to the Patients?

The chair of the advisory committee, Dr. Thomas Whelan, said it was "mind-boggling" that 10 years later there was little more information about safety than there had been in 1991. In our testimony, CPR staff pointed out that the three years of safety data that the implant makers provided was inadequate, and that if the implant makers had completed the studies they started in 1990 there would have

been more than 12 years of safety information. Instead, the implant makers lost track of the patients and had no idea if they were healthy or ill.

The advisory panel seemed ready to reject silicone implants, but at the last minute voted 9-6 to recommend approval, with restrictions. The vote generated a storm of media attention. CPR's President Dr. Diana Zuckerman appeared on NBC's *The Today Show* and PBS's *Lehrer NewsHour*, among others. In addition, Dr. Zuckerman was quoted in newspapers across the country, including *the New York Times*, *the Washington Post*, and *USA Today*. CPR's entire staff worked around the clock to get the word out to women and their families nationwide about the need for an improved breast implant

that was safe and effective enough for women to use without fear that their health might be compromised.

The Seal of Approval?

This brings us to January 2004, when the FDA announced that it would not approve silicone gel breast implants because of a lack of long-term safety data. The law requires the FDA to decide if a product is proven safe. Some critics mistakenly think a product should be considered safe unless there is clear evidence of harm, but that is not what the law says. We applaud the FDA for doing its job to protect consumers. FDA approval is intended to be a gold standard. We're pleased to see that silicone has not tarnished it.

Quotable Quotes: Testimony to the FDA

"Currently, over a quarter of a million American women have breast implant surgery every year. This could be a disaster waiting to happen if silicone implants become available without proper long-term study."

---Nancy Bruning, Breast Cancer Survivor and Author of "Breast Implants: Everything You Need to Know."

"If this is what happened at two or three years using the best plastic surgeons that the company could find to participate in their study, what will happen to women across the country using less experienced doctors and with implants for 10 or 20 or 30 years?"

--- Judy Norsigian, Executive Director, Our Bodies, Ourselves

"Some argue that breast implants have already been studied more than any medical device. If that is true, perhaps there is a good reason. More than \$2 billion in legal settlements might influence the need for research and the incentive for companies to fund such research. Unfortunately, even \$2 billion cannot guarantee good quality research."

---Dr. Martha Burk, Chair of the National Council of Women's Organizations

"As far as we know, the FDA has never taken action against a product because of a sponsor's failure to complete post-approval studies. If you believe that we need more data, you better ask for it now."

---Cindy Pearson, Executive Director, National Women's Health Network

"The company started to analyze the safety of silicone gel breast implants in 1990. They included only 29 breast cancer patients...The company enrolled thousands of patients in their new study, and then failed to follow up on most of them, making that study useless."

---Dr. Diana Zuckerman, President, National Center for Policy Research for Women & Families

HEALTH NEWS WE CAN USE

You read it here first! Here are the latest developments from stories you read in earlier issues of the Voice for Women & Families.



Is There Mercury in Your Sandwich?

After years of refusing to mention tuna fish in their warnings about mercury, the FDA is now telling pregnant and nursing women and parents of young children to limit the amount of tuna they eat. New studies indicate that fresh tuna (used in tuna steaks and sushi or sashimi) and canned albacore (white tuna) have 3 times as much mercury as canned light tuna.

The FDA now warns pregnant and nursing women to eat no more than 6 oz. of fresh or canned white tuna per week, and a total of no more than 12 oz. of any fish. They warn that children should eat even less, but they don't say how much.

Unfortunately, even 6 oz. of fresh or canned white albacore tuna could expose a pregnant or nursing woman to too much mercury, especially if she then ate 6 oz. of other fish.

Based on the newest research, we now recommend avoiding fresh tuna or canned white albacore tuna -- none for children under 6 and no more than 6 oz. per **month** for pregnant and nursing women. We continue to believe that it is safe for them to eat 6 oz. of canned light tuna per **week**.

Hormones and Your Health

The latest research raises new concerns about the risks of hormone therapy. In addition to increasing the risk of breast cancer and stroke, hormone use is linked to greater memory and concentration problems and heart problems -- exactly the opposite of what was expected for this so-called "fountain

of youth." The FDA has come up with a new pamphlet on the topic, available at www.fda.gov/womens/menopause, which urges women to use hormone therapy only if needed for severe symptoms and at the lowest dosage for the shortest period of time possible.

When the studies first warned about the dangers of hormones in 2002, the concern was Prempro and other drugs that combine estrogen and progesterin. Estrogen alone was known to cause uterine cancer but was considered safe for women who had had hysterectomies. Unfortunately, the latest studies show that estrogen alone can cause stroke and should be avoided.

All the negative publicity about hormones has reduced their use, but not as much as the experts advise. Approximately half as many women are still taking hormones, compared to before serious concerns were raised in 2002. That very large number suggests that many women are taking hormones for a longer period of time than is advisable.

Killing Wrinkles?



Artefill, a "wrinkle filler" made of bovine collagen and tiny plexiglas beads, has not been approved by the FDA. We raised concerns about Artefill (Artecoll) last year, when an FDA advisory panel recommended it for approval. We don't know what the future will bring, but the FDA is now urging manufacturers to test all their facial injection products on women and men of color. On the other hand, the FDA approved Restylene for facial injections, even though it was tested on only two African Americans and two Asian Americans.

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An important part of our work is to partner with our affiliates – Women's Centers, Research Centers, and Women's Studies departments across the country. We enjoy getting the word out on their great programs!



Clemson University, originally an all-male military college, admitted their first female students in 1955. Thirty-two years later, Dr. Judith Melton helped found the Women's Studies program, and she's currently the program's director.

"Back in 1987, the concept of 'Women's Studies' was an alien one here. Few students had ever been in an academic environment, whether it be high school or another college, that had gender issue programs. We had our work cut out for us!" Dr. Melton tells *The Voice for Women & Families*.

The program started with a grant from the University of North Carolina. "We had to bring in academics to train many of our professors in feminist theories, because in those days no one came to the university versed in the discipline, unlike now."

"I've seen so many changes since the eighties, particularly in student's attitudes. When I first started at Clemson, not everyone agreed that women should earn equal pay for equal work. Few students understood what date rape meant. Not all women felt that they had the same opportunities as their male counterparts. It's a different world now," Dr. Melton adds.

The upcoming academic year will be the 50th anniversary of co-education on campus. In addition, it's also the ten-year anniversary of the founding of the President's Commission on the Status of Women, an advisory panel that makes policy recommendations to the college president. The commission's current project is a study on women in the workplace which gauges the environment at Clemson for female faculty and staff.

The Commission is also busy planning the Women's Art Project, a biannual festival celebrating women in the arts. Artists come to campus to participate in panel discussions, workshops, and performances. "It's a fantastic way to showcase the contributions of women and have fun at the same time," explains Dr. Melton.

"We're still a rural southern campus with a military background, and we're in the Bible belt. We've made extraordinary strides in introducing young people to feminist concepts and empowering students -- not to take on our ideology, but to stay true to one of the central tenets of feminism: The ability to think for oneself, make informed decisions, and clearly articulate opinions."



The Women's Center at the University of Wisconsin at Madison is another terrific example of how campus programs have expanded over the years -- in this case, to serve not only the intellectual needs of students, but also the daily needs of individuals, families, and the greater community.

The center, with a staff of seven students plus over forty volunteers, administers several programs. "For example, we have a childcare program, where we match student volunteers with families who need an extra hand. Volunteers supply 3-4 hours of free childcare per week. It's a huge help for student parents who are raising children, holding down a job, and attending school," explains Jessica Harrison, the Center's publicity coordinator.

Center volunteers also operate "Kid's Night Out" the last Friday of every month, where student parents can drop off their children for the evening. "Kids love it because it's a party just for them, and it gives parents a weekend night to have some fun, too," notes Harrison.

In addition to services for families, the Center has programs geared toward the individual. "Each semester we choose one topic, whether it be war survivors, loss and mourning, or body image issues, to be the focus of peer-led support groups. We also hold ongoing, news-you-can-use meetings." Every week is a different topic -- building healthy relationships, effective time management, decision-making strategies. "It's important for college age women, many of whom are living on their own for the first time, to have access to a peer group that can help them form healthy habits that they can carry with them through adulthood," says Harrison.

The program also does a great deal of public education. "For instance, bulimia was getting out of control on campus, so we're combating the disorder with our 'bulimia bathroom campaign.' We'll be hanging flyers for our newly launched bulimia support group in women's bathroom stalls all over campus."

"It's been a great experience working at the Center. Not only do I get to help my friends and peers, but I'm learning skills that I will carry with me after college -- although I am having such a great time that I don't want to think about leaving!" sums up Ms. Harrison.

**To join our affiliates program,
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ml@center4policy.org**

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