



THE VOICE for Women & Families

Reaching Out on Campus

Diana Zuckerman, President

Is scientific and medical research being politicized in ways that jeopardize our health and safety? And are young women seeking extreme measures to achieve perfection? Those questions are a major focus of our Center's outreach to students and faculty.

During the 2004-2005 academic year, we traveled to several college campuses. At two schools, we talked about the use and misuse of research on issues ranging from the safety of food (is that mercury in your tuna salad?) to body image (what does the science tell us about the safety of certain medical products?).

At Princeton University, I joined a Nobel laureate, a Member of Congress, and a faculty member at a roundtable discussion about how science is getting politicized, and the impact that has on health and safety. Our standing-room-only event was sponsored by the Union of Concerned Scientists and Princeton Environmental Action.

Rep. Rush Holt (D-NJ), a physicist and former Princeton faculty member, reminded all of us that "politics is the balancing of interests" but ideological and religious factors must be separate from "the gathering and analysis of data." Nobel laureate Eric Weischaus, a molecular biology professor, was able to speak at a level that everyone could understand about how reproductive health debates are ignoring biologi-

cal realities. Weischaus was one of 48 Nobel laureates to sign a statement criticizing the Bush Administration's misuse of science. "I know how hard it is to get a group of scientists, especially Nobel laureates, to agree" to sign anything, he pointed out. Stephen Pacala, professor of Ecology and director of Graduate Studies, discussed how global warming has been mishandled in recent years.

I was glad to be in such auspicious company! I gave several examples of how policy makers have ignored science when it suited them. Using the example of mercury in fish, I described how the most popular fish in the U.S., tuna, was deleted from FDA advisories for pregnant and nursing women and young children, even though almost 1% of women eat so much tuna that they could put their babies at risk for mercury toxicity. (The number of young children at risk is unknown, because scientists don't even know what the safe level is for children). I also showed how research on breast implants has been "spun" by PR experts to make the results sound reassuring even when risks of cancer deaths are significantly increased.

At a similar event at George Washington University, sponsored by the Union of Concerned Scientists and Student Physicians for

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We've Moved!

Our new address is:
1701 K Street, NW
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Overcoming Barriers for Women with Disabilities

"A 42-year-old paraplegic woman notices a lump in her right breast. Her medical provider tells her it is a bulging pectoral muscle from pushing her wheelchair. Later diagnosed with Stage III breast cancer, she dies within 3 years."

"A 69-year-old woman is recovering from a stroke which has left her paralyzed in the right arm and leg. She has always had regular checkups in the past, but now wonders how she is going to climb onto an exam table for a breast exam or stand for mammography."

-Case studies from Breast Health Access for Women with Disabilities
www.bhawd.org

One of five American women has a physical or mental disability, and they face many challenges in getting the health care they need. While there are many barriers, the most challenging is finding doctors who are willing to treat them and facilities with the needed medical equipment.

According to Dr. Margaret Turk, Professor at the State University of New York Upstate Medical University at Syracuse, it is difficult for women with disabilities to get the care they need—including gynecologic services, mental health services, dental care, and vision care. Providing care to patients with disabilities is more time-consuming—it may take several minutes just to help the patient lie down on the exam table. Unfortunately, insurance reimbursement rates are the same for patients with disabilities as for other patients. "Providers lack medical knowledge, experience issues with time and reimbursement, and often hold beliefs and attitudes that interfere with effective communication and patient care," Turk explains.

As an important step forward in improving access to care, our

Center coordinated a national summit in December 2004, "Breaking Down Barriers to Health Care for Women with Disabilities" for the Office on Disability and the Office on Women's Health of the U.S. Department of Health and Human Services. The meeting was also co-sponsored by the Interagency Committee on Disability Research at the U.S. Department of Education.

Dr. Margaret Giannini, Director of the Office on Disability, started the meeting with an ambitious promise: "By the end of today we will have started developing a road map to ensure that all women with disabilities have better diagnoses, treatment, and management of their health care needs than they do today."

The summit brought together 50 invited experts from across the country to explore ways that health professionals and facilities can overcome barriers and provide the best possible care. It featured successful programs that improve access to care and educate providers. The summit participants represented health care associations, legal experts, advocates, health care providers, government officials, and researchers. Participants included experts such as Dennis Smith, Director of the Center for Medicaid and State Operations, Centers for Medicare & Medicaid Services (CMS); Steven Tingus, Director of the National Institute on Disability and Rehabilitation Research, U.S. Department of Education; and Helena Berger, Chief Operating Officer, American Association of People with Disabilities.

"We are now writing an action plan based on the brainstorming of the conference participants who spent the afternoon of the summit working in small groups developing

specific goals and strategies," explains Madeleine Levin, the Center policy analyst who coordinated the meeting. This action plan will be used by the Office on Disability to recommend ways to reduce the barriers faced by women with disabilities.

Goals focused on provider edu-

The summit brought together 50 invited experts from across the country to explore ways that health professionals and facilities can overcome barriers and provide the best possible care.

cation, Medicaid reimbursement, accessibility of medical equipment, and data collection on access to health care services. In the provider education workgroup, participants strategized on the development of a resource center to collect and distribute existing educational resources for all types of providers and for all levels of training. In the financing group, participants worked on a plan for CMS to develop a Request for Proposals for state demonstration projects to waive some Medicaid reimbursement rules for health services for people with disabilities.

The plenary sessions for the summit were webcast live through the Office on Disability web site at www.hhs.gov/od, and a recording can be accessed through December 2005 by clicking on the "Archived Webcasts" section of their web site. The final report also will be posted on the Office on Disability web site later this year. ■

Reaching Out on Campus

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Social Responsibility, I joined Susan West Marmagas from Physicians for Social Responsibility, David Michaels, GWU professor of Occupational and Environmental Health, and Eric Shaeffer, founder of the Environmental Integrity Project. Although some of the examples we gave were different from the Princeton roundtable, the main message was the same: science should not be influenced by ideology or politics.

We also participated in the **Extreme Measures Campus Tour**, aimed at counterbalancing the messages of *Extreme Makeover*, *The Swan*, and other reality programs that are infomercials for plastic surgery. Sponsored by the National Council of Women's Organizations, the tour reaches out to students, coaches, and faculty to discuss the pressures on women to conform to a cultural ideal of beauty that does not occur in nature very often.

At American University and Rutgers University, I joined Jeanine Cogan from the Eating Disorders Coalition and other experts to examine what is known and not known about the causes and consequences of the increasingly popular extreme measures that college women resort to in their effort to feel beautiful.

Rachel Beckman spoke about her personal experiences as a college student with an eating disorder, a heartbreaking saga in which therapists failed to recognize the seriousness of her problems, and sorority sisters shared bulimia strategies instead of encouraging Rachel to overcome her disorder. Her story almost ended in her suicide attempt on campus. Fortunately, a homeless man found her and made sure she received medical help, and her parents found a facility specializing in eating disorders that was able to help her overcome her illness.

Kacey Long spoke about her personal experiences with breast implants, urging the women in the audience to accept their bodies

rather than trying to perfect them, as she had. Although her saline breast implants were removed more than a year ago, Kacey is still making monthly payments to her plastic surgeon and suffering from medical problems caused by her implants.

This is just the beginning of our effort to reach out to more students and faculty. This summer we will work with our interns to develop new strategies to help us be even more effective on a wide range of health and safety issues. ■

Making a Difference

For a donation of \$35 or more, we will send you a copy of *50 Ways to Improve Women's Lives*, a book authored by leading voices on women's issues, including our Center's president Diana Zuckerman.

If you'd like to make a tax-deductible contribution, we hope you will use the enclosed envelope or click "contribute" at www.center4research.org.

Thank you!

What's Happening with Social Security?

Should we be worried about Social Security? Will our check be there for us when we need it? Just when it seemed like President Bush was giving up on his quest to privatize Social Security, there are new plans and new activity on Capitol Hill. As we consider alternatives to the current system, remember:

- The current Social Security system is relatively generous to people who earn the least— especially spouses who give up their jobs or work part-time so that they can take care of children or other family members. Most of these spouses are women.
- Personal, private accounts are based entirely on your income. If you have a high income, you will have a lot of money in your personal, private account. If you earn less, work part time, or take a few years out of your career to care for family members, your personal, private account will suffer.

The transition from our current system to a system that is even partially privatized will cost billions of dollars. One way to save some money to pay for that is to reduce the way benefits are calculated to keep pace with inflation. That's what President Bush is currently recommending: keeping those inflation increases as is for anyone earning under \$20,000, and reducing inflation indexing for those earning \$20,000 or more. This means smaller Social Security checks each month. Anyone earning more than \$20,000, and especially those earning more than \$40,000, would need to depend much more on private accounts, because their benefits under the current Social Security system would decrease dramatically.

The end result: Social Security as we know it would change drastically, to a poverty program rather than a program for all Americans. For more information go to www.center4research.org.

Fibroids: A Common Problem

If you don't have fibroids, you probably know someone who does. Fibroids are extremely common benign tumors in the uterus that occur in 20 - 40% of all women of childbearing age. They come in all sizes — some are so large they can make a woman look pregnant — but shrink at menopause, since they depend on estrogen. African American women are more likely to get fibroids and tend to get larger and more numerous fibroids than other women.

Because fibroids affect so many women and treatment varies widely, our Center recently reviewed current research findings for the treatment of fibroids. This work was funded by the Agency for Healthcare Research and Quality.

In most cases fibroids do not cause any problems, and a woman may not even know that she has them. In many cases, though, fibroids cause symptoms. Whether the symptoms are mild or serious depends on the number and size of the fibroids, and location in the uterus. The most common symptom is excessive menstrual bleeding — some women with fibroids bleed so much that they become anemic. Other symptoms include pelvic pressure, a distended stomach, increased girth, urinary problems, pelvic and back pain, and infertility. Fortunately, it is very rare for fibroids to become malignant.

Treatment Options

If a woman with fibroids is not having symptoms, her doctors typically will not recommend treatment unless the fibroids are very large or growing rapidly. If treatment is needed, there are several options. Most doctors first prescribe hormones, either progestins or a combination of estrogen and progesterone (birth control pills), in addition to recommending over-the-counter

pain medication. In many cases, this will be enough to make the symptoms more manageable or alleviate them altogether.

If medicine alone is not providing enough relief, surgery is an option.

Approximately 600,000 hysterectomies are done each year in the U.S., and fibroids are the leading cause. Hysterectomy is usually effective in alleviating the symptoms of fibroids, and women tend to be satisfied with the results. It is far from an ideal treatment, however, as it is expensive, has a long recovery period, results in infertility, and may lead to complications.

Myomectomy, in which the fibroids are removed while the remainder of the uterus is left intact, is a less drastic option but is only possible in certain cases, depending on the number, size, and location of the fibroids. A potential benefit of myomectomy is that fertility may be preserved. However, fibroids often come back after a myomectomy, and the surgery has the usual risks of bleeding and infection.

Before either hysterectomy or myomectomy, many patients are treated with drugs called gonadotropin-releasing hormone (GnRH) analogues. These drugs shrink the fibroids and thus make surgery easier. Unfortunately, long-term treatment with these medications causes menopausal symptoms.

A new procedure, uterine artery embolization (UAE), is an alternative to surgery. Only about 13,000 UAE procedures took place in the U.S. last year, compared with 600,000 hysterectomies, but so far it appears to be a very successful procedure. First used for fibroids in 1995, UAE involves injecting tiny particles into the arteries that supply the fibroids, cutting off their blood supply. Although studies to date have shown that UAE is effective

Why should a woman living in Georgia be more likely to undergo a hysterectomy than if she lives in New York?

and doesn't cause infertility, most doctors will not recommend the procedure for women who still want to have children. It is not yet known how successful it is in providing a permanent cure for fibroids.

An even newer technology uses ultrasound to treat fibroids. A magnetic resonance imaging (MRI) machine visualizes the anatomy and a focused ultrasound beam heats and destroys the fibroid. The FDA has recently approved a device applying this technology for women who do not desire future fertility, but it has not yet been used in many women.

Despite this range of potential treatments, hysterectomy remains the second most common surgery performed in the U.S. Physicians, policy makers, and patients have voiced concerns about unnecessary hysterectomies and about large geographic variations in the use of hysterectomy. Why should a woman living in Georgia be more likely to undergo a hysterectomy than if she lives in New York?

Evidence suggests that doctors' uncertainty about the appropriate use of hysterectomy is the primary cause of the disparities in treatment. This uncertainty arises in part from lack of research on the effectiveness of hysterectomy compared to alternative treatments for fibroids. Evidence-based information to help doctors treat patients with uterine fibroids remains surprisingly scarce. Hopefully, new research and new technologies will decrease the need for surgery to treat fibroids. ■

Are Dietary Supplements Safe?

Nearly one in five Americans takes dietary supplements, and that number is quickly growing. Why do so many people turn to supplements? Many assume that if a product is "natural," it also must be safe. Advertisers for products containing vitamins, minerals, and herbs repeatedly exploit this assumption. When shopping for natural health remedies, keep in mind that "natural" is not synonymous with safe; for example, arsenic, lead, and mercury are natural but harmful.

When they advertise supplements, manufacturers are required to adhere to Federal Trade Commission (FTC) regulations; their claims must be truthful and substantiated. Claims cannot be "misleading," but in reality, advertisements often stretch the truth. A 2002 FTC report on 300 weight-loss ads, two-thirds of which were for dietary supplements, found many false or misleading statements, including claims of safety made without any scientific data to back them up.

Unlike prescription medications, natural remedies have not been tested and approved. Current guidelines allow supplement manufacturers to sell any product that has not yet been proven dangerous, but companies don't need to conduct studies to determine whether or not the supplements are dangerous.

To complicate matters further, companies are not required to disclose any reports of adverse effects from their products to the FDA. Due to insufficient regulation, risky dietary supplements may remain on the market. It is often only after people die that these dangerous products are banned. For example, ephedra, marketed as a health supplement to lose weight, was popular for years despite safety concerns. It was only after athletes like NFL player Korey Stringer died after using ephedra that research was finally conducted; FDA clamped down, and ephedra was removed from the market. By that time, lawsuits from consumers had dramatically increased, and the companies no longer had a financial incentive to keep selling the product.

Another problem with the lack of regulation is the quality of a product. Even if a natural supplement may be beneficial, there is no guarantee that when you buy a product it actually contains the ingredient it claims to have. An independent laboratory, Consumerlab.com, tests dietary supplements and found that some name-brand supplements contain only a fraction of the ingredient on their labels, and some had none at all. Sometimes supplements can be contaminated. A batch of ginseng supplements sold in Boston was found to be contaminated with pesticide residue and toxic heavy metals like mercury, lead, and arsenic. Sometimes "natural" supplements are "spiked" with prescription medications which are not listed on the label. Researchers found Viagra and Cialis in "natural" sexual enhance-

ment supplements. Some supplements were pulled from the market when they were found to contain a variety of prescription medications that could cause serious complications, including cardiovascular problems, ulcers, or gastrointestinal bleeding.

General Precautions:

When considering a supplement, it is important to take the time to find out if there are risks of dangerous side effects and complications. This is especially critical for pregnant women and nursing mothers. In addition, some supplements can amplify the side effects of prescription medicines or reduce their effectiveness. Always consult your primary health care provider to make sure supplements will not interfere with or aggravate any medical conditions you may have.

- **Supplement-Drug Interaction:** Many natural remedies interact with over-the-counter and prescription medications, either amplifying their side effects or inhibiting their full effectiveness. For example, St. John's Wart, a supplement commonly used for anxiety and mild depression, can interfere with the metabolism of medications used to treat heart disease, cancer, and HIV. St. John's Wart can also interfere with the effectiveness of prescription antidepressants.
- **Interference with Surgery:** The American Society of Anesthesiologists cautions patients against taking herbal remedies for two weeks prior to any surgery. Herbs such as ginseng may trigger changes in blood pressure and irregular heartbeat during surgery, and ginkgo biloba may interfere with blood clotting.
- **Risks During Pregnancy:** Products that are usually safe can be harmful to women who are pregnant or breast feeding. Always check with your doctor before taking any vitamins or supplements. Avoid supplements including black cohosh, blue cohosh, comfrey, dong quai, echinacea, fenugreek, feverfew, garlic, ginger, pennyroyal, rosemary, safflower, saffron, sassafras, tansy, willow bark, and yarrow.

For more info visit : www.center4research.org or www.nccam.nih.gov/health/bottle

Nips, Tucks, and...Designer Vaginas?

Variations in the natural female form used to be accepted, even celebrated. Increasingly, however, these variations are seen not as assets, but as problems to be taken care of by plastic surgeons.

As a result, Americans spent more than \$12 billion on plastic surgery in 2004. Liposuction, breast augmentation, and eyelid surgery were the most popular surgical cosmetic procedures. According to Dr. V. Leroy Young, chair of the emerging trends task force of the American Society of Plastic Surgeons, the plastic surgery procedure with the highest growth rate is also the newest procedure available—genital reconstruction. Once the domain of sex workers, nude entertainers, swimsuit models, and relatively few women with medical abnormalities, vaginal plastic surgery has gone mainstream. Some surgeons reported a four-fold increase in demand last year alone, with patients coming from all over the United States and other countries.

The rising rates of cosmetic surgeries suggest that women are more willing than ever to take risks to enhance themselves.

The Procedure

There are two types of genital reconstruction. Vaginoplasty is the external reconstruction of the vulva. It includes procedures such as trimming the labia minora or majora, reconstructing hymens, elevating the pubis, and unhooding the clitoris. "Vaginal rejuvenation" refers to tightening the vaginal muscles. This type of surgery has been performed in the

United States for nearly 10 years, but until now was typically performed by gynecologists and urologists to treat urinary incontinence, usually as a result of childbirth. Today's vaginal surgery, however, is increasingly becoming the domain of plastic surgeons.

Like any surgery, genital surgery has risks. Serious risks include painful scarring or nerve damage that could result in loss of sensation or hypersensitivity. Another risk is over-tightening of the vaginal walls, which can result in painful intercourse.

Why do women want genital surgery?

Advocates and critics agree that the new popularity of these procedures is caused by the desire for heightened sexual pleasure and more youthful looking genitals. Some doctors claim that the demand for genital plastic surgery is being driven by pornography, now more readily available than ever on the Internet and cable television. Dr. David Matlock, founder and director of the Laser Vaginal Rejuvenation Institute of Los Angeles, explains on his web site that "...many people have asked us for an example of the aesthetically pleasing vulva [so] we went to our patients for the answer and they said the playmates of Playboy." With encouragement from their partners and offers of discounts from their plastic surgeons, patients often have the surgery in conjunction with breast implants or rhinoplasty. Surgeons attract patients with claims that the procedures are "rejuvenating" or "designer."

Success?

Do these procedures work? Like any other type of cosmetic surgery, results can be excellent or disastrous.

Genital rejuvenation is still relatively new, and no good data exist on the number of women who get these procedures, complication rates, or how satisfied they felt with their results. Though many women say they seek out these procedures to enhance their sexual experiences, no research data support claims of increased sexual satisfaction. Importantly, experts say that perceived sexual enhancement as a result of genital reconstruction may be attributed in part to the psychological reaction to the surgery, rather than to physical changes from the surgery itself. Dennis Sugrue, former president of the American Association of Sex Educators, says that "...before even considering an invasive procedure like vaginal tightening surgery, it's absolutely critical for a woman to consult with a sexual health professional to make sure that the cause of the sexual dissatisfaction is thoroughly assessed and diagnosed. Noninvasive treatment procedures should first be employed. Only if all of those steps are taken and fail to bring about satisfaction should surgery even be considered."

What's Next?

Whether genital plastic surgery will ever become as popular and acceptable as other forms of plastic surgery remains to be seen. The rising rates of cosmetic surgeries suggest that women are more willing than ever to take risks to enhance themselves. Though "genital rejuvenation" may not be fully in the mainstream today, it may well be in the future. And if so, what will plastic surgeons come up with next? ■

Dr. Pamela Gallin: A Health Advocate

Advocating on behalf of patients by breaking down the complexities within the medical system is a mission of Board Member Pamela F. Gallin, MD, FACS, author of the recent book *How to Survive Your Doctor's Care*. In fact, this mission is what attracted Dr. Gallin to our Center and prompted her to join our Board of Directors last year. As one of the world's leading pediatric surgeons, Dr. Gallin believes that everyone deserves high quality care.

Dr. Gallin is Director of Pediatric Ophthalmology at the Children's Hospital of New York Presbyterian Medical Center, where she is on the faculty of the Columbia University College of Physicians and Surgeons. Despite this impressive background, expertise, and insider knowledge of the health care system, even Dr. Gallin has, at times, found it difficult to receive the highest quality medical care for herself. "Doctors are patients too," Dr. Gallin notes, "yet, this does not guarantee that even they can get the best care." How you set up your own health care is the determining factor in the quality of service that you will receive.

According to Dr. Gallin, the first and most important step in setting up your own care is choosing the right hospital or medical center for you. That choice will determine every other aspect of your health care, including the quality of your health care providers and the resources available to you. Dr. Gallin offers 11 tips for selecting the right hospital for you. For example, she suggests you ask:

- What subspecialists are available?
- Who staffs the emergency room?
- Is there a pediatric emergency room?
- Is it a designated trauma center?
- Is it affiliated with a medical school?

Dr. Gallin also provides step-

by-step instructions to finding the right primary care doctor and a list of essential questions to ask any prospective physician. Additionally, she provides guidelines for selecting an advocate to help you manage and keep track of your care.

This book, along with Dr. Gallin's previous book, *The Savvy Mom's Guide to Medical Care*, a Book of the Month Club selection and Amazon #1 Parent's Choice, is particularly useful for people in good health. "You can't plan your emergencies," Dr. Gallin warns, which she herself learned recently when her daughter needed emergency surgery while in England. "So it is best to plan and organize your medical records and consider which doctors and hospitals you want to use while you are healthy."

"The idealism I still have about medicine, along with my belief in a patient's right to information, has led me to share what I know and to spell out how to get the fine care that I know is out there," explains Dr. Gallin.

"My goal is to write books that provide useful insight into today's complex medical system, which can often be intimidating, and empower patients to assume a more active role in their own care and the care of their families," she says. She is starting a new book which she hopes will offer even more insight into how to secure the best medical care.

"Medicine is a humanitarian effort," Dr. Gallin observes. Part of attaining that goal is advocating for the rights of patients and helping health care consumers get the information they need to make the best possible decisions. Dr. Gallin notes that "the National Research Center for Women & Families is a very articulate voice with similar goals." With Dr. Gallin on our Board, we plan to develop new strategies to provide useful medical and health care information to families across the country.

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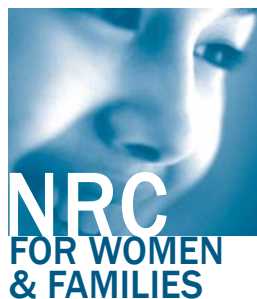
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