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# THE VOICE for Women & Families

## A Surprising Way to Improve Cancer Survival

Billions of dollars are spent on cancer research each year, mostly aimed at developing medication to cure cancer or prolong survival. A new study published in the highly respected *New England Journal of Medicine* shows that a very different strategy may help terminal cancer patients live longer and more comfortably.

Palliative care—often called "comfort care"—helps control pain and other symptoms, rather than treating the disease that causes them. When palliative care was provided to people with metastatic non-small cell lung cancer in combination with cancer treatment, the patients suffered less depression, had a higher quality of life, and lived longer. Paradoxically, they were less likely to choose aggressive medical treatment in their last few weeks or months.

Non-small cell lung cancer is the most common form of lung cancer. Metastatic means that the cancer was caught very late (Stage 4) and has spread beyond the lungs and lymph nodes to other organs like the brain, bones, or heart. When lung cancer spreads like this, it can't be surgically removed and is incurable. Various treatments have been found to prolong life by months and in some cases years, but these treatments have many serious side effects, involve hours of chemotherapy or radiation treatment, and may not provide relief from many debilitating and painful symptoms.

Researchers expected that patients receiving palliative care early on would have a better quality of life than patients receiving cancer treatment alone. But nobody predicted that the palliative care patients would also live longer. Now doctors are wondering: might early palliative care work for other cancers and diseases as well?

### What Is Palliative Care?

The goal of palliative care is to help dying patients live as comfortably as possible during the time they have left and spend meaningful time with their families. In addition to relieving pain, palliative care offers psychological support to the patient and family, and helps the patient and family adapt to life with a serious illness and make decisions about how they want to live and die.

### Why do patients have to choose between comfort and treatment?

In the study by Dr. Jennifer Temel and her colleagues, patients did not have to choose between cancer treatment and palliative care the way patients in the real world usually have to. Half of the 151 patients at Massachusetts General

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## What's Inside



**National Research Center for Women & Families**
www.center4research.org

*We are dedicated to improving the health and safety of adults and children by using research to develop more effective treatments and policies.*

**Cancer Prevention and Treatment Fund**
www.stopcancerfund.org

*Our Cancer Prevention and Treatment Fund helps adults and children reduce their risk of getting cancer and helps everyone get the best possible treatment.*

**CFC # 11967**

# Honoring Foremothers and a Health Research Hero

It's always an honor to thank women who have broken down barriers while improving the lives of others. Our annual Foremother Awards Luncheon took place the Monday after Mother's Day, and was a heartwarming opportunity to recognize three remarkable Foremothers whose accomplishments have touched millions of lives. We also honored **Dr. Catherine DeAngelis**, the first woman editor-in-chief of one of the most prestigious medical journals in the world, for her inspiring work to preserve and increase the integrity of medical research.

**Katharine Weymouth**, CEO and Publisher of the *Washington Post*, gave opening remarks for the third year in a row, saying, "This is my absolute favorite lunch of the year and I am honored to be invited back to do it. Each year this organization recognizes the work of women who have truly changed the world in our area." Ms. Weymouth reminded the audience that they "stand on the shoulders of the women who have come before us," and who "have paved the way for us, and continue to pave the way for us."

Ms. Weymouth discussed the foremothers within her own family. Her grandmother **Katharine Graham** is the most famous one, as the publisher of the *Washington Post* featured in *All the President's Men*. Her great grandmother, **Agnes Meyer**, was also a formidable woman who advocated for public education and the creation of the Department of Health, Education, and Welfare. Both were powerful role models to Ms. Weymouth, who referred to Katharine Graham as "a mother, a wife, and a working woman in what was really very much a man's world then."

## Foremother Honorees

We honored **Ruth Lubic**, who was the first nurse to be awarded a MacArthur Foundation "genius" award and has worked as a nurse-midwife for 48 years. In 1975, she opened the first state-licensed birthing center in America. Ms. Lubic reflected upon the profoundly insensitive medical care women giving birth often received in the 1950s. Describing how women in labor were given heavy drugs "so that they would not remember the experience," Ms. Lubic choked with emotion. "Laboring women—there were no family members permitted—were restricted to a bed with padded side rails so that their erratic drug-induced behavior would not harm them or their fetuses. When moved to the delivery room, their hands were in leather bracelets on the side of the delivery table so that they could not touch their 'clean baby' with their dirty hands."

Ms. Lubic also described recent challenges to improving women's birth experience and birth outcomes. Most alarming, she said, is the ever increasing rate of Caesarean sections, coupled with a rise in maternal deaths. Caesarean sections accounted for about 10% of deliveries in the U.S. in 1975, but by 2007 had escalated to nearly 32%. Meanwhile, maternal deaths more than doubled between 1987 and 2006. These concerns inspired Ms. Lubic to found the Developing Families Center in Washington, D.C. in 2000. The Center has reduced pre-term and low-weight births and lowered rates of Caesarean delivery. Most importantly, the Center has empowered "women to take charge of their health and the health and lives of their families."

Ms. Lubic closed by thanking the National Research Center for Women & Families "for doing so much for mothers and families" and presented a signed poster she had designed to NRC President Diana Zuckerman.

We also honored **Diane Rehm**, the award-winning and much-loved host of *The Diane Rehm Show* on National Public Radio, who has been named "Washingtonian of the Year" and one of the "150 Most Influential People in Washington." Ms. Rehm spoke of her mother and father coming to America from Egypt and Lebanon, respectively, and reflected on being a first generation Arab woman in America. She stated that she did not "have a single book" in her childhood home and, unlike her male cousins, she was "not allowed to enter into higher education."

Ms. Rehm shared her profound appreciation for the turn her life has taken, saying, "The fact that I am in a position now to have my choice of books, and issues, and people to talk with and about is absolutely, for me, the best thing in the whole wide world." Her voice full of pride and gratitude, she mentioned that her daughter is a physician and the mother of two wonderful children: "One generation, one generation and this is what happens. We as women, as people, can do anything."

We honored **Omega Logan Silva** for her accomplishments as the first female president of the Howard University Medical School Alumni Association and as a passionate supporter of women in medicine who has made significant strides for both African Americans and women of her generation. She is a respected advocate for universal health care, and it is through her commitment to public health that she came to be a member of NRC's Board.

Dr. Silva acknowledged that she belonged to an unusual cohort of women: a full quarter of her class in medical school was female, a very high percentage at the time. About half of all medical students are now women, she noted, and "it is predicted that in 2040, there will be equal numbers of men and women doctors." Despite this progress, Dr. Silva pointed out, "We can count the number of women deans on our hands," as well as the number of women CEOs of hospitals, clinics, and insurance companies.

Photo by Gwen Lewis

*L to R: Katharine Weymouth, Diana Zuckerman, Omega Logan Silva, Diane Rehm, and Catherine DeAngelis*

After very humorous remarks about the challenges facing aging women, Dr. Silva concluded by asking everyone in the audience "to encourage leadership in women, help them have a plan to move up as high as possible in whatever field they choose for their life's work."

## Health Research Policy Hero

**Catherine DeAngelis**, Editor-in-Chief of the prestigious medical journal *JAMA (Journal of the American Medical Association)* since 2000, has worked tirelessly to ensure the integrity of research that influences America's medical care. Her recent editorial policy, which insists on independent statistical analyses of studies financed by pharmaceutical companies and other companies whose financial health is affected by study results, will bring greater objectivity and accuracy to medical articles that doctors and patients rely on. This will, in turn, improve the quality of medical care and save lives.

Prior to her position at *JAMA*, Dr. DeAngelis was a dean at Johns Hopkins School of Medicine. She described how troubled she was to realize she was only the 12th female professor in the 93-year history of the medical school. "When I went to the Dean's office a few years later as the Vice Dean for Academic Affairs and Dean of the Faculty," she remarked, "I made sure women were looked at the same way as men."

Through her endeavors to advance the role of women professionally and to boldly challenge the objectivity and accuracy of medical research, Dr. DeAngelis has displayed remarkable leadership. She acknowledged that this is challenging and told us that success requires four qualities: "You have to be tough-minded—not tough, tough-minded. You have to be tenacious. And the hardest thing for women, I think, is you have to have thick skin….but you also have to have a very tender heart."

Closing remarks were made by NRC Board member Judith Harris. She reminded everyone that these luncheons offer us "a time to look back, as we do with deep gratitude, and honor those special women who often have faced enormous challenges and blazed trails and cleared the way for those of us to follow, so that we could have a bit of an easier time finding our way. But it's also been a time to look forward to how much remains to be done."

Ms. Harris emphasized the need for continued support. "Whether we were explaining complicated medical research information to families or health care professionals, or making sense of controversial new research on new vaccines, old medications, or toxic chemicals in toys, we scrutinized research in a way that is unique in Washington—actually calling the scientists directly to find out what their research can tell us and what it can't tell us," explained Ms. Harris.

This year's luncheon was held at the historic University Club of Washington, D.C., and was supported by many nonprofit organizations actively involved in advocating for the health and safety of adults and children, including the American Medical Women's Association, American Association of University Women, American College of Nurse Midwives, Critical Path Institute, Developing Families Center, National Organization for Women, National Women's Health Network, and U.S. Public Interest Research Group.

*To watch remarks in their entirety, visit the NRC for Women & Families' YouTube channel at: http://www.youtube.com/user/nrc4wf*

## Fall 5K Run/Walk for the Cancer Prevention and Treatment Fund

Taking advantage of the fall weather, we held our second 5k run/walk for the Cancer Prevention and Treatment Fund on October 3rd. Once again, the race took place in Arlington, Virginia, on the beautiful Washington & Old Dominion Trail. It marked another great effort in the fight against cancer.

Runners and walkers aged 7 to 65 gathered at Bluemont Park on a sunny morning to get moving for a good cause. Thanks to the generosity of **Giant**, **Whole Foods**, **Bruegger's Bagel**s, and **Caribou Coffee**, racers enjoyed snacks after the race.

It took just 18 minutes and 33 seconds for first-place finisher **Ted Poulos** of McLean, Virginia, to cross the finish line. With a time of 22 minutes and 28 seconds, **Karen Young** of Boyds, Maryland, took first prize among women. Both runners received a gift certificate to **Pacers** running stores. **REI**, **Panera Bread**, **Ben & Jerry's**, and **Lululemon** also donated prizes for the race. For all finish times and rankings, see our website at www.stopcancerfund.org.

**Lisa Weiser**, who participated in memory of **Martha Luque**, was our top fundraiser, raising $500 to help support our online cancer hotline. In addition to Martha Luque, we ran in memory of **Ros Brannigan**, **Renee Harris**, **Micheline Krodel**, and all who have lost their lives to cancer.

We also ran in honor of all cancer survivors, including **Anita Lipman**, **Rob Mostow**, **Carver Sapp**, and **Leo Zuckerman**, thanks to donations from friends and family.

We had terrific support from community businesses including our Gold Sponsor, **NES Associates**, and our Silver Sponsor, **Body Dynamics**. Our Bronze Sponsors were **American Service Center/Mercedes Benz of Alexandria**, **Healthway Natural Foods**, and **REI**. We also had some great volunteers, including GMU's **Alpha Phi Omega**.

Our Government Relations Manager, Paul Brown, organized the race. "We thank everyone who came together to help us prevent cancer. We hope you will join us for our 2011 5k run/walk to celebrate cancer survivors and honor those who have lost their lives to cancer."

## Meet Board Member Ann Braun

Our newest Board member, Ann Braun, brings a unique development philosophy to her work and volunteer activities. She believes that it is essential to "model the type of behavior and values and generosity you'd like to see from those around you. It's up to each of us to set the standard of caring for people."

Earlier this year, Ms. Braun joined the University of Southern California's Keck School of Medicine as Executive Director of Development and Senior Associate Dean for Development. In that position, she is designing a fundraising initiative for USC's academic medical center. She describes herself as a leader who encourages initiative. "It's really our job to get things right," she says, "basically, bringing the Ritz-Carlton standard of service to everything we do."

Ms. Braun is excited about joining our Board of Directors because, "I believe very strongly in the mission. I believe influencing policies and laws and advocating is very important and it's a way of impacting far more people than just one by one. In my previous job at the University of Florida School of Medicine, I worked with your Board member, Dr. Nancy Hardt. Dr. Hardt is a beautiful blend of warmth and intelligence in her advocacy for women and children and the community. I found her to be one of the most likeable and effective leaders I've ever met in academic medicine. I was passionate about what she was doing. I consider it a privilege to be asked to serve as a member of the Board alongside her."

### Working for the Public Good

"I really love what Dr. Darrell Kirch, President of the American Association of Medical Colleges, says about medicine," Braun says, "that it is a noble calling, and that academic medicine is such a precious public good. Very few people realize just how significant the work of educating the next generations of physicians and scientists is. That's important to me in my work, as well as in my volunteer work as a Board member."

We're excited to have Ann Braun join our Board and grateful to Board member Dr. Nancy Hardt for introducing us. We look forward to working with Ann to strengthen our fundraising efforts so that our organization can continue to grow.

## Improve Cancer Survival

*continued from page 1*

Hospital were randomly assigned to get standard cancer treatment and the other half were given palliative care immediately after diagnosis in addition to cancer treatment. The patients that received both cancer treatment and palliative care reported a better quality of life (measured by three different quality-of-life questionnaires). In contrast, quality of life for patients receiving only cancer treatment decreased.

Only 16% of patients who received palliative care plus cancer treatment had symptoms of depression, compared to 38% of patients getting only cancer treatment.

Most surprising, patients receiving palliative care plus standard treatment lived about **2 months longer** than the other patients, despite less aggressive treatment in their final weeks and months. This suggests that treatment focused on the whole patient and not just fighting the cancer may be more cost-effective as well as improve quality of life and survival time.

More patients in the group assigned to standard cancer treatments received aggressive end-of-life care, compared to patients who received palliative care plus cancer treatment. The researchers defined aggressive end-of-life care as chemotherapy during the last two weeks of life, no hospice care, or hospice care for only the last few days of life.

Continuing with chemotherapy until their last days costs patients and their families more (medical insurance often does not cover the full cost) without necessarily buying them more time.

Hospice care is a form of palliative care for those who are near death, and can be provided at home or in a hospice. It can help minimize visits to the emergency room and hospitalizations, common occurrences for late-stage cancer patients.

The researchers explain their findings in several ways:

- Quality-of-life improvements and fewer depression symptoms may have helped patients live longer.

- By pursuing less aggressive treatment, the patients enrolled in palliative care may have benefited from fewer toxic side effects, which may have increased their will to live.

- Palliative care patients got earlier referral to hospice programs, and preparing for death in a supportive environment may have helped prolong life.

During the 2009 debates on health care reform, some people mistakenly equated end-of-life palliative care with ending people's lives through so-called "death panels." This new research is an example of how palliative care can be used early on and as a complement to standard cancer treatment to improve the quality of life and even prolong life for patients who are very ill.

Doctors are not trained to discuss end-of-life issues, nor are they currently reimbursed for time spent on such discussions with patients. Most insurance plans will not pay for palliative care or will only pay for a very limited time, unless the patient has decided to stop other medical treatment. As a result, many patients do not know about palliative care or are not willing or financially able to consider it.

The new study gives reason to hope that patients with other terminal diseases might also benefit from palliative care in the same way that these lung cancer patients did. The idea that fatally ill patients can potentially live longer and more comfortably with the help of early palliative care in addition to standard medical treatment deserves immediate study.

*We don't accept funding from drug companies, so we rely on the generosity of individual donors.*

*We welcome donations to the National Research Center for Women & Families by check or online (www.center4research.org).*

*You can donate to our Cancer Prevention & Treatment Fund by check, online (www.stopcancerfund.org), or federal employees can designate* ***Combined Federal Campaign # 11967***

### Leaving a Legacy

If we can't live forever, at least we can help keep our legacy alive, as well as the legacies of those most important to us. Creating an internship is a wonderful way to honor a family member or a friend, or to create your own legacy.

Internships provide training that can result in a lifetime of good works. You can donate to legacy internships or establish a new internship or fellowship through a donation of cash or stock, a distribution from a retirement plan or life insurance policy, or a will.

For more information, call Brandel at (202) 223-4000 or e-mail her at bfb@center4research.org.

# POLICY MATTERS

## Watching Out for Dangerous Drugs and Improving Medical Care

As a consumer watchdog, our goal is to help protect patients and consumers from unsafe and ineffective prescription drugs. Through FDA Advisory Committee testimony and research, we fight drugs with risks that far outweigh their benefits.

### Cancer drug: Avastin

In July, Dr. Zuckerman testified on the use of popular cancer drug Avastin for treatment of Stage 4 breast cancer. Although Avastin can temporarily slow the progression of cancer, it is a highly toxic drug with serious side effects. The research clearly shows that breast cancer patients taking Avastin were more likely than those who didn't to have a heart attack, stroke, or gastrointestinal perforation, and as a result had a reduced quality of life and tended to die a little sooner.

"Even when these side effects aren't fatal, they have a terrible impact on the cancer patient's quality of life," Dr. Zuckerman said. Avastin also costs approximately $80,000 per breast cancer patient, in addition to the cost of the additional hospitalizations caused by the drug.

The Advisory Committee voted to withdraw approval of Avastin for treatment of breast cancer. The FDA is expected to make a final decision in December 2010, but whatever it decides, Avastin will still be available since it is approved for other types of cancer, for which its benefits seem to outweigh its risks.

### Anemia Drugs

In October, Dr. Zuckerman testified about her concerns regarding several anemia drugs intended to improve the health of patients undergoing chemotherapy or dialysis. Although the drugs are effective for some, those with a history of cancer are more likely to die if they take the drugs.

"In the ideal world, doctors would clearly communicate with patients about the best treatments, and doctors would read all the latest research. We need to find a way to make sure that the patients most likely to benefit from these drugs have access to them." Zuckerman continued, "it is imporant that patients with a history of cancer and others who are most likely to be harmed by these drugs no longer are prescribed them."

### Diabetes drug: Avandia

Millions of diabetics take Avandia to control their blood sugar levels. In fact, Dr. Zuckerman's father took Avandia until she reviewed a new study a few years ago and immediately had him switch to a safer, more effective diabetes drug. Although experts have expressed concern about Avandia's risks, the FDA kept it on the market with label warnings. "Avandia is great at lowering blood sugar, but the whole point of that is to reduce the risk of death," Dr. Zuckerman explains. Avandia increased patients' heart attack risk by 43% compared to other, safer diabetes drugs.

We urged the FDA to take Avandia off the market, as the European Medicines Agency recently did. Instead, the FDA has decided to increase warnings and severely restrict use, which eventually is expected to result in a de facto removal from the marketplace. Those restrictions will not be in place until at least 2011.

### Weight Loss Drugs

Dr. Zuckerman also testified in September about the weight loss drugs Meridia and Lorcaserin. "Obesity can be deadly by causing diabetes and heart disease and increasing the risk of cancer, but most people don't lose much weight on Meridia so it's not saving lives," Zuckerman said. Most committee members agreed and voted to withdraw FDA approval; a month later, the manufacturer voluntarily withdrew Meridia from the market. The advisory panel also recommended that the FDA not approve Lorcaserin, which was found in a recent study to be ineffective and have unpleasant side effects, including possible cognitive damage.

Dr. Zuckerman was quoted in the *New York Times* on diet drugs when the FDA refused to approve a third drug, Qnexa: "The vast majority of people taking them don't stay on them long enough to get any health benefit." She also told reporters that we urgently need better diet drugs—ones that really work and aren't so dangerous.

### Prostate Cancer Drug

Provenge was approved by the FDA for Stage 4 prostate cancer, but Medicare hasn't decided whether to pay for this very expensive drug, which costs $93,000 per patient. We are examining the research to determine the safety and effectiveness of Provenge. Our view so far is that the cost should not determine Medicare coverage if Provenge is significantly safer or more effective than other treatments.

The goal should be for Medicare to provide the best possible medical care but not waste taxpayers' dollars on treatments that are less effective than other drugs. For example, there is evidence that Provenge may harm rather than help patients under 65 (who are too young for Medicare anyway) but no research specifically on patients who are 65-70. We are strongly urging that research be funded to determine more specifically which patients are likely to benefit from Provenge and other very expensive drugs, and which are most likely to be harmed.

# Obesity Costs Women More Than Men

By now, nearly everyone knows that being obese is bad for your health, but did you know that it's also bad for your wallet? This is especially true for women.

Obesity is usually defined as being 20% over ideal weight or as having a BMI of 30 or higher (BMI—body mass index—is calculated using height and weight). Obese people are more likely to suffer from chronic health problems, such as diabetes and heart disease, and don't usually live as long as people who are not overweight. The latest research indicates that obese people are at a higher risk for colon cancer and obese women are also more likely to get breast cancer and endometrial cancer. Obese people also experience a diminished quality of life because of physical difficulties and discrimination. While many reports have discussed the "cost to society" of obesity, none have looked at the additional costs in dollars for an obese woman or man.

A recent study by Avi Dor and his colleagues at the School of Public Health at George Washington University found that **it costs an obese woman $4,870 more per year to live in America** than a woman who is a healthy weight. Obesity costs less for men—an additional $2,646 per year. Part of those costs are paid directly by the obese person and part by employers and the government.

## What Kind of Costs?

The researchers examined all the data available on direct medical costs, work-related costs, and personal costs. Direct medical costs include out-of-pocket as well as insurance-covered expenses related to doctor visits, hospital care, and medications. Diabetes and cancer are expensive to treat. Work-related costs include differences in wages, missed workdays, and disability payments. Personal costs refer to the yearly dollar amount spent on life insurance and transportation.

The researchers believe that their estimates are on the low side because they did not take into account other expenses that are typically higher for obese people, such as clothing, air travel, or furniture.

## Lower Wages

Most surprising, the researchers discovered that obese women do not earn as much as women of "normal" weight, but there are no differences in wages for men who are obese compared to "normal." The likely explanation is that there is a double standard that places greater emphasis on women's physical appearance than men's. If obese women's lower wages were the result of something else, like lower productivity or more missed days of work, wouldn't that be true for obese men as well?

## Overweight vs. Obese

This study also found that there is an added cost for being overweight (BMI of 25 to 29.9) in America, although not nearly as high as the cost of obesity. It costs an overweight woman an extra $524 per year to live in the U.S., compared to $432 extra per year for men. If a person is only obese by a few pounds, losing those pounds could potentially save quite a bit.

The economic downturn has affected nearly all of us, but this study reveals that its impact may be even greater for people who are overweight or obese. If health concerns aren't enough incentive to change eating and exercise habits, knowing economic costs might be.

NRC
FOR WOMEN
& FAMILIES

# We've Moved!



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## In this Issue of **THE VOICE**




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