

The National Research Center for Women & Families

We are dedicated to improving the health and safety of adults and children by using research to develop more effective treatments and policies. The Cancer Prevention and Treatment Fund is our major program.

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The Cancer Prevention and Treatment Fund

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

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Cancer Hotline: Helping a Woman Who Helps Millions

Dr. Harriet Lerner, a psychologist and therapist, is best known for self-help books that make it easier for us to navigate the swamps and quicksands of difficult relationships. You've probably heard of her *New York Times* bestseller, *The Dance of Anger*, and, most recently, *Marriage Rules: A Manual for the Married and The Coupled Up*.

We first met Harriet over the phone when she was diagnosed with breast cancer. Harriet tells us, "I'm a person who's given advice to millions of people worldwide. But, when I was diagnosed, well, I was the one who needed expert advice." She agreed to be interviewed for our newsletter and to serve on our Advisory Board.

Q: How did you react to your diagnosis of invasive breast cancer?

A: I didn't ask, "Why me?" My mother and sister had the diagnosis, as did many of my dear friends and colleagues. The question I asked myself was, "What do I do now?" There were as many different answers to this question—from doctors and just plain folks—as there were people that I asked. Some recommendations were presented

as The Truth of The Universe, others as, "It's simply a personal choice."

It wasn't only the differences of opinion that threw me. Around certain decisions there was 100% agreement among professionals, and it still didn't feel right for me. They all assumed that, of course, I would want reconstruction so that I wouldn't be "disfigured" and that I should make this decision before I even had the surgery to remove the cancer.

Q: Where did you turn?

A: While I've had a lifetime of experience giving clear and calm advice to others, I

needed some good advice myself this time. To be honest, I couldn't think straight at all because anxiety turned my brain to mush. While readers of my books surely assume that I'd be a clear-thinking researcher on my own behalf, nothing is further from the truth.

What I had going for me was the ability to ask for help. I believe that we're here to help each other out. I'm also lucky to be well

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NRC in the Headlines!

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We can't be bought.

Our Center doesn't accept funding from drug companies or device manufacturers, so we rely on the generosity of individual donors. You can donate online at stopcancerfund.org.

Lawsuits pile up over popular birth control pill

Chicago Tribune
September 15, 2013

New tanning bed warnings proposed

Washington Post
May 7, 2013

Still more work to do on cancer

Washington Post
August 6, 2013

New Scrutiny for Medical Devices?

New York Times
November 18, 2013

New Concerns on Robotic Surgeries

New York Times
September 9, 2013

Boomers' embrace of devices gives rise to new med-tech age

Star Tribune
September 15, 2013

Here's a recent sample of our impact on the news:

We were quoted in the **New York Times** in an article about external cardiac compressors—life-saving devices for emergency situations—and how the FDA never required studies to prove that they are better than manual CPR.

NRC President Diana Zuckerman explained in a letter to the editor of the **Washington Post** that our Center has been working for over a decade on reducing patients' fear and confusion about "cancers" that many experts now agree are not really cancer, because they don't spread and aren't harmful.

We were quoted in the **Chicago Tribune** saying that Yaz and other oral contraceptives that contain drospirenone increase the risk of dangerous blood clots and "shouldn't be on the market because there are so many safer alternatives."

In the **Star Tribune** and in a **Healthcare Policy Podcast**, Dr. Zuckerman explained to readers and listeners how medical devices are tested and approved, an increasingly important topic as boomers go bionic, replacing hips, knees, and other body parts. Did you know that many devices that our lives depend on were not studied in clinical trials?

We were quoted in the **Washington Post** advocating for stronger regulation of tanning beds, describing the FDA's proposal as "very weak."

We were quoted in the **New York Times** in an article on the under-reporting of problems with robotic surgery in general and the da Vinci system in particular, reminding readers that reports of serious problems that are made to the FDA represent only "the tip of the iceberg."

Dr. Zuckerman was interviewed by **NBC television** about a permanent form of birth control called Essure that has been causing thousands of women debilitating pain: "We really have no idea what the long-term risks are" of these metal coils implanted in women's fallopian tubes.

Dr. Zuckerman wrote articles for the **Huffington Post** and **Rodale.com** about unanswered questions about Essure birth control and about the government shutdown over the Affordable Care Act.

Brandel France de Bravo was interviewed by the Spanish language TV network **Telemundo** about the increasing number of teenagers getting cosmetic surgery.

Personalized Medicine: Hype or Hope?

You've probably seen headlines declaring the "new age of personalized medicine." Maybe you've wondered: if medicine is undergoing a radical shift, shouldn't my doctor have mentioned it at my last check-up?! What do these changes mean *for me*?

If you know your blood type, you already know something about "personalized medicine." So, what's really new here?

Scientists now realize that a lot of the names we use for diseases, like "lung cancer" or "high blood pressure," are too general. In fact, what we think of as a single "disease" is often collections of many conditions that experts have lumped into the same category. For example, there are many types of breast cancer, such as ER+, Her2+, or triple negative. Each of these "subtypes" has its own genetic cause and comes with different treatments. With this in mind, "personalized medicine" is all about getting as specific as possible. It's about figuring out which specific type of disease a patient has and using that information to provide the best treatment for him or her.

Sounds great, right? Research suggests that this approach can result in better health for patients. For example, a recent study showed that lung cancer patients whose treatment is chosen based on their particular genetic information live longer. During the last two years, one out of three new drugs approved by the FDA falls into this "personalized medicine" category. And medical schools are developing "personalized medicine" programs to train the next generation of doctors in these new methods.

What's in it for you?

As a patient and consumer, what is the best way to take advantage of this new approach to medical care? Fortunately, you don't need to get an advanced biochemistry degree to learn about personalized medicine, although it might help to become familiar with a few keywords (see box at left). And, when you need to make a medical decision or even if you are just having a routine exam, it's a good idea to ask your doctor if there are any aspects of your care that

could be tailored to your age, sex, weight (BMI), genes, or other factors.

However, with anything new, there are kinks to work out. For most people, and for some of the most common diseases, scientists and doctors still don't know how to use our genetic information to help us. In addition, our genetic information is not the whole story, anyway. For instance, if you get genotyped and give the results to your doctors, they are likely to glance at them skeptically and tuck them into a folder. Most diseases are *not* the result of just your genes: you can have mutations or a bad pair of



genes, but if you don't smoke, put on weight, or come into contact with certain chemicals, the genes that increase your risk may never cause you any harm.

The pharmaceutical industry is adapting a little more quickly to personalized medicine than other parts of the healthcare system. The potential profits for them are great. Although personalized medicine means developing drugs targeted to relatively small numbers of patients, when proven effective, those drugs can command a very high price tag.

So what should *you* do? Should you get tested now or wait for the prices to come down and the medical profession to catch up to the science? That depends partly on whether you are a "plan-ahead-better-to-know-now" person or a worrier for whom every black cloud is a tornado. Would finding out that you are at high risk for Parkinson's disease, for which there is no cure, ruin your life or make you appreciate each healthy day all the more?

Whatever you decide, you need to know that your genetic information can be used against you. It *can't* be used to deny you healthcare coverage, thanks to the 2008 Genetic Information Nondiscrimination Act and the 2010 Affordable Care Act ("Obamacare"), but it *can* be used to deny you life insurance, disability insurance, or long-term care insurance. Until those road blocks are removed, many people use pseudonyms when they get gene testing of any kind. ■

Words to Know

DNA or gene sequencing: a sample such as blood, saliva, tissue, or simple cheek swab is used to determine your genetic information, including any gene mutations you might have.

Genomics: the large-scale, computer-based study of genetic information.

Genotyping: a test in which a particular, small portion of your genetic information is analyzed either by sequencing or another method. This type of testing can be done for as little as \$99 using a kit sent to your home.

Mutation: a small change in genetic information (DNA) that is thought to contribute to a health condition.

Whole exome sequencing: a test in which your genetic information is analyzed partially—only the part which is used to make the body's building blocks. This costs about \$500.

Whole genome sequencing: a test in which all of your genetic information is analyzed. This costs \$3,000 to \$5,000, but the price is expected to drop further.

Foremother Awards

Inspiring Women and Health Organizations: Our 2013 Honorees

Reporter **Cokie Roberts** and former **Congresswoman Lindy Boggs** were our first “Mother-Daughter” Foremother honorees at our annual Awards luncheon. This year’s Foremothers also included **Dr. Vivian Pinn** and **Mary Hager**. For the first time, our Health Policy Heroes were three nonprofit organizations: **Consumer Reports**, the **ABIM Foundation**, and the **National Physicians Alliance**, all honored for their groundbreaking *Choosing Wisely®* campaign.

“This is our favorite day of the year,” said NRC president Dr. Diana Zuckerman, as she looked around the magnificent ballroom of the Cosmos Club. This historic private club for Washington, D.C.’s movers and shakers didn’t even allow women to become members until 1988. The Awards luncheon is always held on the Friday before Mother’s Day, in honor of the accomplishments of the Foremother honorees who broke down barriers for other women and made major contributions to the health and well-being of women and families. Tickets are available to the public.

Foremother Honorees

The highlight of each year’s luncheon is when the Foremother honorees speak briefly about how times have changed—or haven’t—for women.

Cokie Roberts spoke on behalf of her 97-year old mother, Foremother honoree **Lindy Boggs**, who remained seated but looked on proudly. When Lindy Boggs won a special election in 1973 to fill her deceased husband’s seat, she became the first woman elected to the U.S. House of Representatives from Louisiana. During her nearly two decades in Congress, she effectively fought for civil rights and women’s rights. Ms. Roberts captured her mother’s iron-fist-in-a-velvet-glove character with this anecdote: While serving on the Banking Committee, Representative Boggs noted that the proposed Equal Credit Opportunity Act of 1974 banned discrimination against credit applicants on the basis of race, color, religion, national origin, or age. In long hand, she added “or sex or

Photo Credit: Kate Pisano



Left to right: Mary Hager, Cokie Roberts, Lindy Boggs, Dr. Diana Zuckerman, Dr. Valerie Arkoosh, Tara Montgomery, and Dr. Vivian Pinn.

marital status.” “I’m sure it’s just an omission on your part,” she explained with southern tact to her fellow representatives who had drafted the Act. It wasn’t, but much to policymakers’ surprise, the bill became law with her addition.

Cokie Roberts also shared her own experiences, starting out in journalism at a time when “it was legal to say ‘we don’t hire women to do that.’” The Civil Rights Act passed shortly after Ms. Roberts graduated from college, but that did not apply to women. “It took a lot of brave women,” Ms. Roberts reminded us, to get employers and society at large to shift their views. Named one of the 50 greatest women in the history of broadcasting, Ms. Roberts has shaped society’s views—not just of what a woman journalist can achieve, but any journalist. She can be heard and seen regularly on *NPR*, *ABC News*, and *This Week with George Stephanopoulos*.

We recognized **Mary Hager**, one of journalism’s women pioneers, for her years of outstanding reporting on the major medical stories of our time. She began her career in the 1960s as a newspaper reporter before becoming an editor at *Life*, and then a correspondent and editor for *Newsweek* for 23 years. She covered the mysterious epidemic that came to be known as AIDS, tobacco company cover-ups of the risks of smoking, toxic waste at Love Canal and other SuperFund sites, and the lack of safety studies for implanted medical devices.

As a reporter, Ms. Hager met NRC president Diana Zuckerman when Dr. Zuckerman was a Congressional investigator scrutinizing the risks of medical devices in 1990. Nine years later, when NRC was founded, Ms. Hager became a member of our Board of Directors. Ms. Hager spoke movingly of her experiences on these and other major health stories, including her reporting of the parents featured in the book and movie *Lorenzo’s Oil*. “A reporter

Photo Credit: Sarah Deutsch



is only as good as her sources,” she explained, praising NRC as a great source of objective information. Although Ms. Hager is retired from journalism, she hasn’t put away her computer, and continues to write for the Institute of Medicine, the World Bank, and other organizations.

In her remarks, **Dr. Vivian Pinn**, former Director of the Office of Research on Women at the National Institutes of Health (NIH), advised the audience to “not think that just because we’ve made progress, that it is all accomplished.” She remembers a time when one of her classmates at the University of Virginia’s (UVA) medical school complained that Dr. Pinn’s acceptance in the program took the place of “some better-qualified man.” She made us all laugh when she shared: “I like to show my graduating class picture where I’m there, but he flunked out.” Dr. Pinn was the only African-American and the only woman in her graduating class at UVA.

Photo Credit: Sarah Deutsch



Left to right: Tara Montgomery, Daniel Wolfson, and Dr. Valerie Arkoosh

Dr. Pinn’s career has been devoted to ensuring that women have a place at the research table, as researchers and as patients. During her 20-year tenure as the key women’s health expert at NIH, she served as Co-Director of the Women’s Health Initiative, NIH’s 15-year study of postmenopausal women. Its key finding was that hormones do not need to be “replaced” after menopause and that hormone therapy increases the risk of heart disease, stroke, and breast cancer. “This study has saved so many lives, and we thank Dr. Pinn for that,” Dr. Zuckerman pointed out.

In a personal thanks to Dr. Zuckerman, Dr. Pinn praised NRC for “doing so much to protect women’s health and being a strong, forceful voice warning about unsafe medical products.”

Health Policy Heroes

For the first time, we honored organizations rather than individuals: the **ABIM Foundation** (American Board of Internal Medicine

Foundation), **Consumer Reports**, and the **National Physicians Alliance**.

These three nonprofit organizations created the *Choosing Wisely®* campaign, which aims to reduce unnecessary medical tests and

ineffective treatments and improve the quality of medical care for all of us. Starting with 15 recommendations released in 2011 by internal medicine physicians, family practice doctors, and pediatricians, *Choosing Wisely®* has grown to more than 135 recommendations from 50 specialty medical groups (and counting!) about tests and treatments that are needless, wasteful or harmful. Each specialty provides its own list of “Five Things Physicians and Patients Should Question.” For more information, see www.choosingwisely.org or visit www.center4research.org and type “choosing wisely” in the search bar to see recommendations listed for

children, women, men, and seniors. Cancer patients can visit www.stopcancerfund.org and type “choosing wisely” in the search bar.

Accepting the award on behalf of the ABIM Foundation, **Daniel Wolfson**, Executive Vice President and Chief Operating Officer, had this to say about *Choosing Wisely®*: “People are attracted to this in a way that has captured the attention of physicians and consumers.” **Tara Montgomery**, Director of ConsumerReportsHealth.org, said, “We’ve reached 80 million consumers in the first year of this campaign—that’s just the beginning!” **Dr. Valerie Arkoosh**, Senior Policy Advisor of the National Physicians Alliance, thanked the National Research Center for Women & Families “for adding this wind to our sails.”

We at the Center want to wish *Choosing Wisely®* smooth sailing! ■

We Thank These Wonderful Supporters of Our Awards Luncheon

Platinum Sponsors: American Association for Justice, the Cooper-Rothenberg group at MorganStanley, and Verizon Foundation

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Stop Cancer Now!

A Race and a Cause

This year's *Stop Cancer Now! 5k and Fun Run* was inspiring for many participants as well as the donors who supported them.

The heart and soul of the day are the teams, large and small, who run in honor of cancer survivors and in memory of friends and loved ones lost to cancer. We were proud to have 23 teams this year—too many to describe them all in this article, but you can read about them on stopcancerfund.org. Our top teams were **Team Bob Knuff**, running in memory of Bob Knuff; **Team Lyla**, running for Lyla, a cancer patient who is only a year and a half old; **5K for Mom**, with team leader Jim Parsons, who ran our 5k for the 3rd time, this time for his mom who is now cancer free; **Running and Remembering Dana Wolfe**, an enthusiastic triathlete who recently passed away from leiomyosarcoma; **Strike Out Cancer**, running in memory of Robert Hruz; **Team Russo Audas**, running in honor of Tiffany Russo's parents, who are both cancer survivors; and **Team Olsons**, a team honoring cancer survivors in 5k organizer Kristin Olson's family, including her father, who had the fastest time in his age group.

All the teams were inspiring and we were very glad to give them the opportunity to honor their loved ones. The story of **Team Bob Knuff** was especially moving because Bob's family and friends came together just a few weeks after he died of carcinoid cancer, a rare type that is usually very slow growing. Bob was diagnosed in February 2010, at the age of 48, when he seemed to be in perfect



Left to right: Ben Knuff, Abby Knuff, Michele Knuff, Katelyn Bowers, Kim Bowers

health. Told by his oncologist that many people lived for 10-20 years with this cancer, Bob took the monthly medication the oncologist recommended and continued to live a full, healthy life. Two years later, however, doctors discovered carcinoid tumors had crushed his spine, which required surgery and was followed by chemotherapy. Once again, Bob's family thought he was on the road to recovery. By the spring of 2013, however, Bob's health had drastically deteriorated and the oncologist informed the family that there was nothing more that could be done. Not willing to give up, Bob sought a second opinion from a specialist in carcinoid cancer at Johns Hopkins, which is only 75 miles from Bob's home. It was from this specialist that Bob learned that he could have received a different type of chemo when first diagnosed that has been very successful for carcinoid cancers.

Could Bob's life have been saved had he received this drug sooner? That is a question that haunts the Knuff family and the reason why they are determined that other families not have to suffer because of lack of expert, up-to-date research information about cancer treatments.

We ran in honor of:

Jerry Bernstein ♦ Bill Hansen ♦ Lyla Juarez ♦ Anita Lipman
♦ Edith Mostow ♦ Rob Mostow ♦ Douglas Olson ♦ Patricia Olson ♦ Donna Prisnock ♦ Evie Shears

and all cancer survivors

We ran in memory of:

Dena Brown ♦ Georgia Brown ♦ Mary Ann Chasen ♦
♦ Dhanesh Dalal ♦ Ryan Atherton Ely ♦ Sherry Grandjean ♦
♦ Robert Hruz ♦ Abdul Jabbar ♦ Bob Knuff ♦
♦ Jennie Manning ♦ Dana Elizabeth Wolfe

and all those lost to cancer

Our top fundraisers:

Michele Knuff, Margit Olson, Alicia Hruz, Brittany Wilson,
Tiffany Russo, Michael Jones, Steven Chasen, Monali Malaveetil, Jim Parsons, Karla Baires, Lewis Braml, Karin Argueta, Denise Sorrell, Josmin Khatun, Terri Azie

Thanks to all of our fundraisers for all your hard work, support, and dedication!

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Bob Knuff

Bob's widow, Michele Knuff, told us that participating in the 5k "was truly an uplifting, spiritual day for us. I am so happy to have been able to share our story. It has helped me immensely, and knowing it has

touched others is what we hoped would happen. I am dedicated (as well as our two children Abby, 15, and Ben, 14) to help raise awareness, share our story, and help others in any way that we can. I deeply feel that there is a purpose to all the madness Bob and I went through and that one day I will fully understand. In the meantime, I want to direct my energy in a most positive way."

Thanks to the support of Loudon County's Tuscarora High School, which Abby and Ben Knuff attend, the Athletic Department raised \$550 in honor of Bob Knuff, primarily as part of the ticket sales for a Freshman and a Junior Varsity football game in October. That generous donation will support our Cancer Hotline, as will the \$2,000 that Team Knuff raised for the 5k.

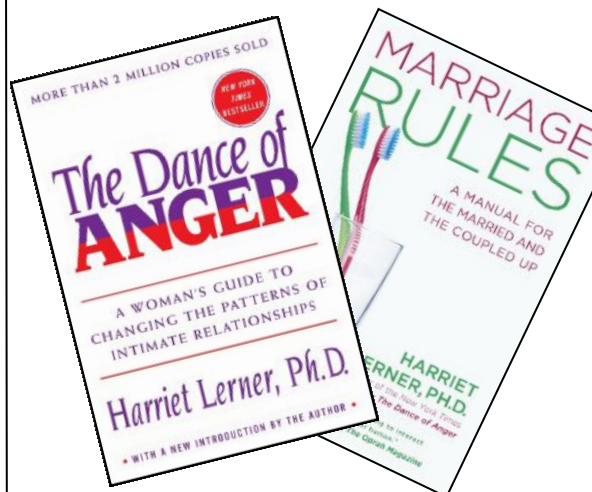
The focus of the Cancer Prevention and Treatment Fund is on using the research that has already been done to prevent cancer—and get the best treatment for those who need it. Families such as the Knuffs have learned the tragic truth that some patients are getting treatment that isn't as effective as it could be. With the support of families across the country, the Cancer Prevention and Treatment Fund is reaching out so that it won't happen again. This race supports our Cancer Hotline, which is a major way that patients and their families can find us and get the help they need to get the best possible treatments.

In addition, we help men and women learn what they and their family members can do to reduce their chances of getting cancer. We've helped get BPA, phthalates, and other cancer-causing chemicals out of water bottles, baby bottles, toys, and many other products in our homes.

The winner of our 5k was Stefan Batory, who was visiting D.C. from Poland, with an impressive time of 18:03. The top female runner was Brittany Wilson, who finished in 20 minutes and 59 seconds. Sisters Emily Makhija (9) and Kate Makhija (7) triumphed in the 1-mile fun run. ■

Continued from page 1

networked. So I asked several key people to do the research for me and find the best, most trustworthy organization I could turn to. My "investigators" agreed that I should turn to the Cancer Prevention and Treatment Fund.



Q: What was your experience?

A: Your organization was like a life preserver that I could grab on to. It's a nonprofit that wasn't selling me anything and that presented objective facts and up-to-date research without pressuring me to do one thing or another. The written materials were easy to read and understand (and free).

I also had the chance to talk to a great person on the phone (also free) who didn't overload the circuits by giving me too much information. She was obviously up on the latest research findings, and I ended up learning new facts that turned out to be pivotal in my decision-making.

I should add that my husband, Steve, was on the phone with me taking notes, since—as I mentioned—I have the brain of a reptile when survival anxiety kicks in.

When I later learned more about the organization, I was impressed and heartened by your integrity and your enormous, wide-ranging accomplishments on behalf of cancer patients and their families.

Q: How are you doing now?

A: I'm doing great. And there's been no second-guessing about the decisions that the Cancer Prevention and Treatment Fund helped me to make. I'm so grateful. ■

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Leaving a Legacy

Is there someone you would like to honor? Internships and fellowships provide training that can result in a lifetime of good work. Honor a loved one through a donation of cash or stock, a distribution from a retirement plan or life insurance policy, or a will.

For more information, contact Brandel at bfb@center4research.org



Help us Brainstorm!

Have you ever had trouble remembering our name? You're not alone, and that's why the **National Research Center for Women & Families** is considering changing its name!



Our ideal name will be shorter, more memorable, and better reflect what we do.

To many people “Women & Families” means “women and children,” but we work on behalf of men as well. We conduct and analyze research to help individuals improve their health and to help policy makers and opinion leaders decide which health programs and strategies work best—but “health” isn’t even in our name!

Send any suggestions by December 10 to info@center4research.org.

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The Voice Issue 23



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