



NATIONAL CENTER FOR HEALTH RESEARCH

The Voice For Prevention, Treatment And Policy



Biennial Report 2015 - 2016



MESSAGE FROM THE PRESIDENT



In 2015 and 2016, we helped thousands of adults and children get the best possible medical treatment, we published articles in medical journals that will help physicians provide better treatment, and we had a major impact on the many invisible government policies that can reduce or increase our risk of cancer, heart disease, diabetes, and other major diseases. Here's how:

- ◆ Our health hotlines served women, men, and children across the country. We helped people decide which screening tests and treatments were best for them, and which were likely to do more harm than good. We helped people reduce their risk of illness and choose the safest and most effective treatments.
- ◆ We urged the Food and Drug Administration (FDA) to require long-term studies of safety and effectiveness for all medications, medical devices, and vaccines so that consumers could make well-informed decisions.
- ◆ We persuaded the federal government to make sure that everyone has access to information about the safety and effectiveness of specific medications and medical devices, and to strengthen the safeguards that protect patients and consumers.
- ◆ We testified before the Environmental Protection Agency (EPA) Scientific Advisory Panel on chemicals that disrupt hormones, which can cause both defects and diseases.
- ◆ We helped persuade state legislators to change laws that had allowed toxic chemicals in furniture and curtains that then ended up in the dust and air in our homes.
- ◆ We testified before the FDA to ensure that medical products are analyzed for their effectiveness in women, people of color, and people over the age of 65. Unfortunately, this is not always the case.
- ◆ We trained 100 patient advocates from across the country on how to make their voice heard to improve medical research on treatments and prevention.
- ◆ Our study of Alzheimer's Disease treatments, published in the international journal *BMJ*, found that drugs that looked promising in early studies were found to be ineffective and sometimes dangerous in better designed studies (known as Phase 3 clinical trials).
- ◆ We published a study in *JAMA Internal Medicine* scrutinizing 18 ineffective cancer drugs still on the market. We found that only one was proven to improve quality of life, and these new ineffective cancer drugs cost just as much or more than the ones that are effective – up to \$170,000 per patient.

- ◆ Our published study of cardiac implants, joint replacements, and other medical implants found that most implants are not proven safe or effective in clinical trials before the FDA allows them to be sold in the U.S. In fact, most manufacturers have ignored the law requiring them to make scientific information available to the public about any studies that might help patients or doctors decide which implants are the best and worst.

Whether we were explaining well-established and complicated scientific information to families and the medical community, or making sense of controversial new research on vaccines, medications, or toxic chemicals in our homes and communities, we scrutinized research and provided useful, understandable, and unbiased information to patients, policy makers, consumers, and the media.

Our research and advocacy work continues to represent the interests and needs of all the men, women, and children who are left out of policy debates and life-saving public health decisions. As always, we will continue to advocate for all Americans on matters that are crucial to the health of adults and children nationwide.

Diana Zuckerman, Ph.D.

PROGRAM AND POLICY HIGHLIGHTS

Our Largest Program: The Cancer Prevention and Treatment Fund



New Study Explains Why So Many Cancer Drugs Don't Work

Cancer drugs often drain a patient's energy and joy for living, but don't always provide much benefit. In some cases, the cancer may stop growing within a few months and even begin to shrink, but ultimately the patient doesn't seem to live even a day longer.

A key problem is that cancer drugs do not have to be proven to prolong anyone's life in order for the Food and Drug Administration (FDA) to approve them. And once the drugs are approved, thousands of patients start taking these drugs and paying for them, despite the lack of evidence of a meaningful health benefit. However, the FDA does require that companies keep studying the drugs to find out if those medicines are actually extending lives.

Unfortunately, many of these drugs do not help patients live longer or better. In a recent study, only five of 36 cancer drugs that were approved between 2008 and 2012 were proven to help patients live longer. Eighteen drugs (50%) failed to extend life and 13 (36%) have unknown impact on survival because no data on them are available to the public. Since companies are very good at sharing information when their drugs

are proven effective, experts assume that means those 13 drugs are not proven to work.

Our Cancer Study

In November 2016, the National Center for Health Research published a new study in *JAMA Internal Medicine* looking more carefully at those 18 ineffective cancer drugs. We found that only one was proven to improve quality of life – which isn't surprising, since cancer drugs so often cause nausea, vomiting, hair loss, and exhaustion. Two made quality of life worse, and the other 15 new cancer drugs either did not improve quality of life (6), or there is not enough evidence to know if they do or not. We also looked at the cost of those cancer drugs and found something that doctors, patients, family members, and lawmakers need to know: **the new cancer drugs that are not proven to benefit patients in any way cost just as much as the ones that are effective – up to \$170,000 per patient.** In fact, the most expensive of the 18 cancer drugs was a thyroid cancer drug (Cabozantinib, also called Cabometyx or Cometriq) that had no benefit to survival compared to placebo, and also caused patients to have a worse quality of life.

Meanwhile, the ineffective cancer drugs remain on the market, and Medicare and insurers are still paying for

them. When we asked FDA officials why they take so long to rescind the approval of ineffective cancer drugs, they stated that they still think those drugs might be effective, but that it is difficult to prove.

They pointed out that once a cancer drug is approved, it is very difficult to keep patients in a clinical trial long enough to know if the drug actually saves lives. We agree it is difficult; if a patient is in a clinical trial and not doing well, he or she is likely to drop out, whether they are on the new drug, old drug, or placebo.

In other words, the FDA is approving cancer drugs on short-term, inconclusive data knowing that we'll never know if they are safe and effective or not.

Patient-Provider Communication for Thyroid Cancer

Patient-provider communication is a complicated issue, especially as it relates to something so complicated and stressful as cancer screening, diagnosis, and treatment.

With partial support from the Patient-Centered Outcomes Research Institute (PCORI), we're planning a research project to determine the best strategies for communication between health professionals and patients regarding thyroid cancer. Topics could include screening, diagnosis, and deciding whether treatment or monitoring is the appropriate choice for ambiguous diagnoses.

In 2017, we will host a brain-storming session with patients, physicians, and researchers from Sloan Kettering, Georgetown, and George Washington University.

"Hopefully, every woman finds her way to your website. Your article has helped me arm myself with information I will need to select the right surgeon." —Annamaria Piccolo, Prospect, Oregon

"I sailed through the surgery, and am thrilled – a dramatic change in course for me after discovering your work. My gratitude to you is beyond words." —Harriet Lerner, psychologist and best-selling author

Working to Reduce Unnecessary Mastectomies

Every year, more than 250,000 women are diagnosed with breast cancer or "pre-cancerous" conditions such as ductal carcinoma in situ (DCIS) that may never become cancer. DCIS and other types of very early breast cancer will sometimes go away without any treatment. Treatment is almost always chosen, however, because experts cannot yet predict which cancers will go away and which will become dangerous.

Even so, experts agree that more than 75 percent of these women do not need mastectomies if they have access to other, equally safe treatment options. Yet, as unbelievable as it may seem, in some parts of our country, medically unnecessary mastectomies are increasing, not decreasing.

Some women will undergo a mastectomy because the surgery is less expensive than lumpectomy—a decision made by their insurance company, not by them. Some will be so frightened by the word "cancer" that they will make a hasty treatment decision they will later, and forever, regret. Fully informed of their options and free to choose, some women will decide to have a mastectomy that is not medically necessary, but thousands more will never even be told when equally safe—and sometimes safer—alternatives are available. NCHR is working with Congress, health professionals, and insurance companies to ensure that patients can get second opinions, and to improve the quality of care available to all patients.

By explaining complicated research results in clear, everyday language and making that information widely available, we can reduce the number of mastectomies and improve cancer treatment at the same time. We can reach this goal by making sure that

women understand their treatment options, doctors communicate more clearly with their patients, insurance companies cover the best treatments, and doctors and patients know the best ways to prevent cancer.

In 2016, we conducted a pilot study at the breast clinic at the University of Maryland Medical Center in Baltimore. We interviewed women regarding a hypothetical DCIS diagnosis. Half the women were given the typical explanation of DCIS, while the other half were given a new type of explanation, equally accurate but without the term "cancer." We are evaluating whether different descriptions of DCIS affected anxiety levels and treatment choices.

Which Diagnostic Tests and Treatments are Best?

Every year, the FDA reviews thousands of new diagnostic tests and other medical devices and allows them to be sold—without first requiring clinical trials. As long as the products are considered "substantially equivalent" to others on the market (a loose definition that does not require that they be made of the same material or use a similar mechanism of action), they can be sold in the U.S.



It's not surprising, therefore, that many of these devices are later recalled because they are found to be dangerous. In addition, the vast majority of prescription drugs and implanted devices are approved on the basis of short-term safety and may not be proven safe for long-term use. Some prescription drugs for common ailments like diabetes can even increase the chances of patients developing cancer. We are working to improve these policies to prevent products that are meant to help us from harming us instead.

In 2015 and 2016, we worked with Congress to prevent the passage of legislation that would lower the scientific standards for approval of drugs and devices by the FDA. We were able to improve the legislation, but ultimately some standards were lowered in the final version of the bill, called the 21st Century Cures Act, which was signed into law in December 2016.



"I'm a cancer survivor myself and love to donate to the cause as much as possible. Keep up the good work and thank you. It's your research that has saved my life."--Shane King, Wichita, Kansas

Prevention and Patient Safety

Safety and Effectiveness of Medical Products

Our work on the safety and effectiveness of medical products has made us a very visible presence in the media, at the FDA, in the nonprofit health policy and consumer community, and increasingly among health policy researchers and scholars.

We are one of the most active public health organizations on FDA issues.

As can be seen in the list of activities below, we influence legislation, hold briefings on Capitol Hill to educate Congressional staff and other interested individuals, meet with Members of Congress and their staff; publish in medical journals and on popular websites; and speak at dozens of public FDA meetings, either as an invited speaker or during the Public Comment Period at FDA Advisory Committee meetings. No other nonprofit organizations participate at close to that level; at many meetings, we are the only public health/consumer safety entity that is speaking.

We conduct research that can improve healthcare, and we publish the results in medical, public health, and policy journals.

In addition, we are fighting to:

- Improve the quality of healthcare through better use of comparative effectiveness research.
- Promote safer and more effective medical devices, such as joint replacements, mesh, mammography, contraceptive devices, power morcellators, spinal implants, cardiac implants, and breast implants.
- Promote safer and more effective pharmaceuticals, including Yaz and other birth control pills containing drospirenone.
- Ensure that antibiotics are safe and effective, and reduce resistant bacteria by preventing the overuse of older antibiotics in animals and humans.
- Improve legislation and transparency to ultimately improve FDA decision-making and Medicare coverage.

For several years, we've been on the forefront of efforts to ensure that medical products have been adequately tested and analyzed in **diverse populations** to determine safety and effectiveness for women and men, people of color, and adults of all ages. We have approached this issue by helping to write and support legislation, by testifying about the lack of such information at FDA public meetings, by conducting research to

document the lack of such data, and by meeting with decision makers at the FDA and Congress.

Despite our small size, NCHR continues to be instrumental in organizing nonprofit organizations to fight for safer more effective, and more affordable medical products, and is the major

consumer voice on medical devices. We help nonprofit organizations, consumers, and media who turn to NCHR for unbiased information on a wide range of controversial topics, including compounding pharmacies, diet drugs, contraceptives, antibiotics, surgical mesh, and medical device safety standards and inspections.

Helping Women Gain Insurance Coverage for Breast Implant Removal

We have surveyed and assisted more than a thousand women with implant problems. Many had previously tried but failed to get insurance coverage to remove their problem breast implants.

Insurance coverage for implant removal is somewhat complicated, but is sometimes possible thanks to the Affordable Care Act, which prevents exclusions due to pre-existing conditions. Nevertheless, surgical removal is only considered "medically necessary" for a few reasons, such as silicone leakage or chronic pain. Many women have other implant problems, such as leaking saline implants or autoimmune reactions, which insurance companies do not consider sufficient justification for covering removal. We are helping women with implant problems obtain coverage for removal when they can meet the criteria, and if not, we encourage them to consider other ways to afford removal.

We also provide women with a credible source of information about breast implants at www.breastimplantinfo.org. Unlike most breast implant websites, we are not selling anything. That means the information on our website is not paid for by plastic surgeons or breast implant makers who want these women as customers. The website provides the most accurate information available, so that women can make choices that are best for them.



"Dr. Zuckerman's...ability to touch on very important issues of health in a small amount of time was not only informative, but contributed immeasurably to the success of our kickoff." —Sammy Payne, Deputy Chief of Staff G-8, United States Army

Environmental Health Issues

We continue to be a major voice regarding the dangers of hormone-disrupting chemicals for human health. Our current works builds on our successful fight in Congress in 2008 to get phthalates banned from children's toys and products.

Phthalates are hormone-disrupting chemicals used to soften plastic that have been linked to birth defects in baby boys, including abnormal genitals, testicular cancer, and liver problems. Despite well-funded, repeated efforts by industry to overturn the law since 2008, those dangerous chemicals are still banned from children's products.

Originally developed as a synthetic estrogen that was replaced by DES, **BPA** is currently used in hard plastic products and is also commonly found in the lining of food and beverage cans. BPA leaches out of the plastic, and the CDC reports that it is in the bodies of more than 93% of Americans. Studies suggest a link between BPA exposure and early puberty, infertility, and prostate and breast cancer. We have been interviewed by reporters about our concerns for pregnant women and children, and testified about the risks before the FDA, and legislative committees in Maryland, Virginia, and Washington, DC. Thanks to our work, companies have voluntarily stopped making baby bottles and infant formula cans with BPA.

Our efforts regarding BPA and phthalates are now focused on getting these dangerous chemicals removed from the packaging used for foods, including canned foods, beverages, and frozen meals.



Unnecessary Radiation

Whether from cell phones, unnecessary CT scans, or mammography that is done too frequently, radiation can increase the risk of cancer even as radiological devices can contribute to easy communication or better medical diagnosis. We are fighting to reduce unnecessary radiation exposure, especially for vulnerable populations such as young children.

We know that most people are not going to stop using cell phones, but they can lower their exposure and risk. Here's how:

- ◆ Limit the number and length of your calls.
- ◆ Use hands-free devices, put the cell on "speaker phone," or hold the phone away from your ear.
- ◆ When speaking on your cell phone, alternate sides.
- ◆ Limit your cell phone use in rural areas or anywhere reception is poor. More radiation is emitted when you are farther from a cell phone tower.
- ◆ Text message instead of talking, but never while driving!

- ◆ Avoid keeping your cell phone in your pocket, bra, or anywhere close to your body while it is turned on.

Keeping Babies Safe in the Home

The National Center for Health Research supports strong safety standards for products in our homes, especially when those products can harm our children and infants. In 2015, we supported the Keeping Babies Safe's (KBS) petition requesting a ban on supplemental mattresses for play yards with non-rigid sides.

At least 21 infants and toddlers have died, wedged between a supplemental mattress and a play yard or portable crib.

To comply with safety standards and avoid suffocation hazards, play yards are made with mattresses that do not exceed 1.5 inches. However, 3-inch supplemental mattresses (which do not meet the play yard safety standard) are often sold side-by-side with play yards. This is why consumers often assume that they are supposed to be used together.



***The Evidence is In:
Obesity and Lack of
Exercise Increase the
Risk of Early Puberty
and Several Types of
Cancer***

Everyone knows about the obesity epidemic and its impact on diabetes and heart disease, but obesity can also increase your chances of developing cancer. Girls and boys are starting puberty as early as 8 years old, and one reason is that obesity affects hormones—and that could also increase the risk of breast cancer, prostate cancer, colon cancer, and some other cancers.

The risk of obesity may be increased by BPA, phthalates, and other chemicals that influence hormones and fat cells. Regardless of the cause of obesity, however, the evidence is now clear that it increases the chances of developing several types of cancer.

In addition to our activities regarding BPA and phthalates described in the previous section, the National Center for Health Research scrutinized new research to determine other potential causes of weight gain.

Most people are unaware of some popular prescription medications

that drastically increase appetite and, in turn, obesity. These include “atypical antipsychotics” (such as Seroquel, Risperdal, Zyprexa, and Abilify), which are taken by more than 30 million Americans each year.

Can weight loss products make you healthier? Most of these products help with weight loss at first, but many people gain the weight back within a few months. We are urging the FDA to require long-term studies so that patients know whether these products will improve their health.

***Remember – we’re
always here for you!***

We assist individuals through our online and telephone helplines, and those services increased dramatically in 2016. In some cases, we spend hours on the phone talking to a patient or family member, and hours more providing useful information via email. In other cases, we provide one or more email responses to questions that patients, family members, consumers, or health professionals have about preventing or treating specific types of cancer or other diseases. We also provide free patient booklets or other materials that we have developed or adapted from the NIH or other unbiased, expert sources.

We provide policymakers, health professionals, and other opinion leaders with an unbiased explanation of scientific data so that they can make educated decisions that affect everyone in our nation. Our research and advocacy work represents the interests of ordinary women and families, who are often left out of policy debates. We educate leaders in our nation’s capital and across the country.

Health hotline
info@center4research.org

Cancer hotline
info@stopcancerfund.org

"The American system works on checks and balances and it helps me sleep better at night knowing you all are keeping government agencies honest." —John H. Powers, III M.D., Olney, Maryland

Congressional Testimony, Briefings, College Lectures, and Speeches



The National Center for Health Research is one of the most active public health organizations on FDA and other issues focused on the quality of medical care. Since we do not accept funding from pharmaceutical or device companies, we are one of the very few objective voices speaking on behalf of better, safer treatments.

Our most important work for 2015 and 2016 has been to fight Congressional and FDA efforts to lower the safety and efficacy standards of drugs and devices.

It took 2 years for Congress to pass the 21st Century Cures Act. The first version, introduced in 2015, had numerous provisions that would drastically lower FDA approval standards. In response to our criticisms, it was improved, but continued to lower FDA standards. However, it included billions of dollars of mandated additional funding for NIH, and for that reason it passed the House of Representatives in July, 2015. The Senate HELP (health) Committee passed 19 related bills in the Spring of 2016, but none were as damaging to patient safety as the 21st Century Cures Act. For approximately 6 months, we successfully encouraged the Senate Democrats to reject the worst sections of the House bill. However, after the November, 2016 election, the Senate Democrats decided to compromise with the House bill, over the objections of

many consumer and public health experts. The 21st Century Cures Act became law in December, 2016.

Here are examples of our efforts to educate policymakers and the public about ensuring that medical products are safe and effective:

- ◆ Dr. Zuckerman was asked by FDA staff to meet to discuss the proposed monograph to improve evidence on over-the-counter medications in December 2016.
- ◆ Dr. Zuckerman and coalition members met with FDA Commissioner Robert Califf to discuss our concern about safety and effectiveness of medical products in December 2016.
- ◆ Dr. Zuckerman was invited to speak about the problems with the 21st Century Cures bill at a Congressional briefing in the U.S. Senate in November 2016.
- ◆ Dr. Zuckerman testified before the FDA commissioner and an FDA panel in opposition to off-label promotion of medical devices in November 2016.
- ◆ Dr. Zuckerman was an invited speaker on a panel on the role of FDA in the opioid epidemic at the National Academies of Science, Engineering, and Medicine in November 2016.
- ◆ Dr. Zuckerman, former FDA consultant Madris Tomes, and women harmed by Essure and breast implants expressed their support for Ariel Grace's Law by meeting with the senate health committee staff in September 2016.
- ◆ Dr. Zuckerman was an invited speaker at a panel sponsored by Harvard Medical School on the role of patients and other advocates in FDA decision-making in Cambridge, MA, in September 2016.
- ◆ Dr. Zuckerman was an invited speaker at Hubweek Panel, "FDA and the Drug Approval Process: Is It Really Broken?" in Boston in September 2016.
- ◆ Dr. Zuckerman met with FDA officials at their request to discuss sunscreen issues in March 2016.
- ◆ Dr. Zuckerman met with government health officials to discuss enormous increases in prescription drug prices and how the lack of data regarding the efficacy of drugs approved by expedited pathways negatively affects prices in February 2016.
- ◆ In October 2015, Dr. Zuckerman was an invited speaker at the National Physicians Alliance annual conference about legislation that would lower FDA standards.
- ◆ Dr. Zuckerman was an invited speaker to discuss the 21st Century Cures Act at a Politico luncheon at the Newseum in October 2015.
- ◆ Dr. Zuckerman and coalition members met with Acting FDA Commissioner Stephen Ostroff to discuss our concerns about 21st Century Cures legislation lowering FDA safety and efficacy standards in September 2015.
- ◆ Dr. Zuckerman was an invited speaker on the impact of environmental exposures on cancer at Hopewell in Baltimore in July 2015.
- ◆ In April 2015, Dr. Zuckerman gave a talk about preventing cancer to the Charter100 group in Washington.
- ◆ Dr. Zuckerman was an invited

COMMUNITY OUTREACH AND EDUCATION

Patient Training Workshops

Pharmaceutical and device companies are supporting many patient organizations, encouraging them to urge the FDA to approve drugs and devices more quickly. However, those patient groups have rarely focused on safety issues, or on other outcomes important to patients.

With partial support from the Patient Centered Outcomes Research Institute (PCORI), we hosted free workshops in November 2015, and June and October 2016 to train patient advocates about research on the safety and effectiveness of drugs and medical devices, and how to contribute to better research studies by representing patients' perspectives in meetings with the FDA, NIH, university researchers, and nonprofit organizations.

Patients and family members from across the country learned about the health and quality of life outcomes that matter most to patients. These workshop participants formed the USA Patient Network, which consists of patients, caregivers, and their friends and family members that are united by a common goal: to make sure that medical treatments are as safe and effective as possible. The USA Patient Network includes patients concerned about cancer and other serious diseases. We will be holding one more workshop in 2017.

To find out more about the USA Patient Network, visit their website at www.USAPatientNetwork.org.



"Our voices will get even stronger! Honored and privileged to have attended Patient Advocacy workshop by NCHR. Thank you Dr. Diana Zuckerman and staff, this was life changing."

- Chandra Dealessandro

In Unity, there is Clout

The National Center for Health Research has a primary role in coordinating the Patient, Consumer, and Public Health Coalition, which includes dozens of well-respected nonprofit organizations, including but not limited to: American Medical Student Association, American Medical Women's Association, Annie Appleseed Project, Breast Cancer Action, Breast Cancer Consortium, Center for Medical Consumers, Consumers Union, DES Action USA, Jacob's Institute of Women's Health, National Consumers League, National Physicians Alliance, National Women's Health Network, Our Bodies Ourselves, and Washington Advocates for Patient Safety (WAPS).

We hosted numerous coalition meetings, strategy sessions, and nationwide efforts to help consumers understand new health information in 2015 and 2016.

Patient Booklets

We continued to distribute electronic and hard copies of the following patient booklets, which have been updated as important new research results are made available:

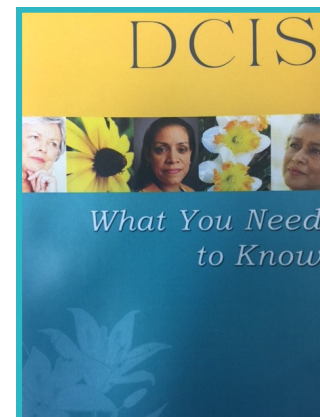
Prostate Cancer Screening: What You Need to Know. This 10-page booklet provides the information that men need

to know to make informed decisions about if and when they should be screened for prostate cancer. If they've already been screened for cancer, the booklet explains what it means if their test showed they had prostate cancer. It is available on the Cancer Prevention and Treatment Fund website.

Surgery Choices for Women with Early Stage Breast Cancer. This 24-page booklet gives women the information they need when confronted with an early stage breast cancer diagnosis. It is also available on the Cancer Prevention and Treatment Fund website.

DCIS: What You Need to Know. This patient booklet explains DCIS in

everyday language and enables women who have been diagnosed with it to make informed treatment decisions. To date, we have distributed 1,369 free hard copies of this 32-page color booklet to medical centers, physicians, and individuals. It is also available for free on the Cancer Prevention and Treatment Fund website.



Information for Medical Professionals

Fast Facts on DCIS for Medical Professionals. This fact sheet summarizes the conclusions of the NIH Consensus Conference on DCIS and subsequent research on long-term patient outcomes. More than 450 hard copies have been distributed, and it is also available for free on our Cancer Prevention and Treatment Fund website.

Health Policy Hero Awards Luncheon

Every May, we hold an awards luncheon to honor Health Policy Heroes for their work improving the lives of people across the country. Our 2015 Health Policy Heroes were Dr. Amy Reed and Dr. Hooman Noorchashm, two tireless advocates for safe and effective medical devices. While a physician at Harvard Medical School, Dr. Reed became a patient. During her routine hysterectomy, Dr. Reed's surgeon used a power morcellator, not realizing a cancer was hidden inside a fibroid. The morcellators pulverized the cancer, spreading it throughout her abdomen. Since then, the couple has become the most well-known patient advocates in the country, determined to make sure no one else gets harmed by a medical device that is not proven safe and effective for everyone.



In 2016, we honored LeeAnne Walters and Marc Edwards. LeeAnne Walters is the Flint, Michigan, stay-at-home mother who was getting nowhere trying



to convince state and local officials that there was something seriously wrong with their water. She started investigating the lead levels, and contacted Marc Edwards, an environmental engineering professor from Virginia Tech and MacArthur Genius award winner. In 2004, he had helped shed light on lead in drinking water in Washington, DC and has spent thousands of dollars of his own money to investigate the lead disaster in Flint's water supply and elsewhere across the country. Together they contacted the EPA, and Miguel del Toral did all he could to make sure the Flint water would be made safe, despite misinformation from official sources.

Lap-a-thon

We held our annual Stop Cancer Now Lap-a-thon at Tuscarora High School in Virginia in April 2015 and November 2016. The Lap-a-thon raised money for our online cancer helpline, which provides free information to anyone who contacts us at info@stopcancerfund.org.

The Lap-a-thon was the brainchild of Michele Knuff, and her children, Abby and Ben, in honor of Bob Knuff. "It was such an uplifting day, full of very fond memories of loved ones, new stories to hear and people to meet, and helping others in their fight against cancer," Michele told us.

Participants celebrated cancer survivors and honored those who lost their lives to



cancer, either by running, sponsoring, or pledging. Participants registered for teams or as individuals. At the end of the 2015 Lap-a-thon, all the balloons representing different cancers were gathered into one large bouquet of color.

"We read the names of all the friends and loved ones that we were honoring. It was a powerful moment as we watched in silence as the balloons were released skyward," described Cancer Prevention and Treatment President, Dr. Diana Zuckerman.

To read more about this event, see photos, and view results, please visit www.stopcancerfund.org/events/lap-a-thon.

5K Walk

On April 2015 and 2016, Sherina Garner organized a 5K walk in memory of her mother, who passed away from lung cancer. All proceeds went to the Cancer Prevention and Treatment Fund to help others affected by cancer through our online cancer helpline. Thanks to Sherina and her friends for this wonderful and moving tribute!



"You are a champion of many and I appreciate all you do." —Jackie Lombardo, Charlottesville, Virginia

Internships



Nisa Hussain, Miriam Mosbacher

The National Center for Health Research was assisted by more than 20 impressive interns in 2015 and 2016, including students from Tulane University, Amherst College, University of Maryland College Park, University of Pennsylvania, George Washington University, American University, Smith College, UCLA, Cornell University, UC Riverside, and Yale University.

Interns can focus on health communications, outreach, marketing, or policy, and gain a wide range of experiences on Capitol Hill. Interns learn about the Washington, D.C. policy scene while working on communicating about a range of health issues. Interns gain experience writing and editing articles, reports, and press releases, and using the Internet to influence people and policies. They also develop their research skills and learn how to communicate effectively with patients and consumers.



Miriam Mosbacher, Nisa Hussain, Hannah Kalvin

Ruth Nadel Internship



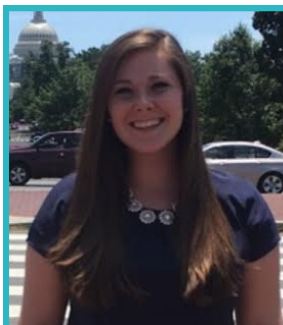
Ruth Nadel

As the Ruth Nadel Intern in 2015, Caitlyn Brooks managed outreach to college campuses about the risks of Yaz birth control compared to other birth control pills. She also helped organize our fall Patient Advocacy Workshop (see page 9). This internship was made possible by friends of Ruth Nadel, who has worked tirelessly on women's health issues for decades. Ruth turned 102 in 2016.

Caitlyn Brooks holds a B.A. in Biology with a certificate in Culture, Health, and Science from Mount Holyoke College.

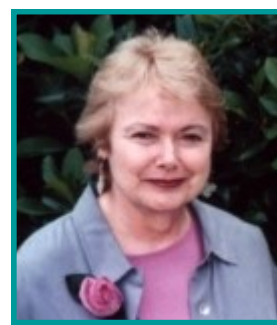
Our 2016 Ruth Nadel intern was Natalie Rosseau. One of Natalie's major projects was ensuring women's access to medically necessary procedures, as well as collecting data and analyzing health insurance plans as a part of the NCHR Affordable Care Act project.

Natalie is a Phi Beta Kappa graduate of Cornell University, with a BA in History and minors in Law & Society and Inequality Studies. She is passionate about providing patient-centered and culturally competent clinical care, and plans to go to medical school in 2017.



Natalie Rosseau

Marcy Gross Internship

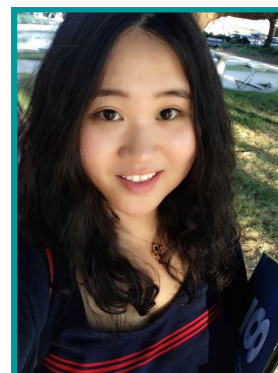


Marcy Gross

Our 2016 Marcy Gross intern was Mingxin (Mandy) Chen. Mingxin focused on health economics and policy issues related to women's health and cancer treatments. Mingxin focused on policy issues related to women's health, the need for medical products to be proven safe and effective for the many kinds of patients who are going to depend on them: women and men, people of color as well as whites, and adults over 65 as well as those under 65. She reviewed published research on possible causes of cervical cancer.

Mingxin graduated from Johns Hopkins Bloomberg School of Public Health in May 2016 with a Master of Health Science in Health Economics.

As a nationally-respected senior official with the U.S. Department of Health and Human Services, Marcy Gross helped build the foundation for federal policies regarding sexual assault and other women's health issues. She was a strong supporter of NCHR until her death in 2005.



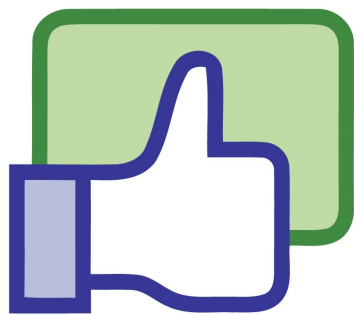
Mingxin (Mandy) Chen



Internet and Social Media

Our websites, www.center4research.org and www.stopcancerfund.org, provide free information on a wide range of topics important to anyone who wants to improve their health, learn more about medical devices or treatments, and reduce their chances of getting cancer or increase their chances of getting effective treatment. Our web presence continues to grow, as we almost doubled our web users from 2015 to 2016 to 1.5 million users.

Our online health hotlines enable anyone to obtain free information about their own personal concerns by contacting info@center4research.org or info@stopcancerfund.org. We help hundreds of individuals each year with their questions regarding prevention and treatment options.



We also reach a broad virtual audience through social media on our Facebook pages (www.facebook.com/nationalresearchcenter and www.facebook.com/CancerPreventionandTreatmentFund) and Twitter accounts (@NC4HR and @cancer_fund). At the end of 2016, we had over 1,500 twitter followers, and about 1,500 Facebook followers.

Public Service Announcement with Actress Elisabeth Rohm

We were thrilled when Elisabeth Rohm enthusiastically agreed to film a public service announcement for the Cancer Prevention and Treatment Fund in November 2016. She's been in TV shows such as *Law and Order*, *Hawaii Five-O*, and *The Last Ship*, and in many films, including starring alongside Jennifer Lawrence in *American Hustle* and *Joy*. She joins the cast of *Jane the Virgin* in 2017.

She is particularly interested in our unique work to prevent cancer and keep cancer-causing chemicals out of children's products as well as our neighborhoods, food, and homes. As a devoted mother, she shares our concerns that her daughter might be exposed to these chemicals on playgrounds and in toys, soda cans, and even pizza.

You can find a link to this video at the bottom of our homepage at www.stopcancerfund.org, or visit www.stopcancerfund.org/in-the-news/press-releases/actress-elisabeth-rohm-urges-give-back-join-fight-cancer.



MEDIA AND COMMUNICATIONS

In 2015 and 2016, the media turned to the National Center for Health Research for timely health and medical information from a credible source. We responded to frequent requests from reporters and producers across the country for information, comments, and interviews. In September 2015, Dr. Zuckerman was invited to be a blogger for the website of *Our Bodies Our-selves*. She has also been invited to write syndicated op-eds that have been published in *Chicago Tribune*, *Sacramento Bee*, *Lawton Constitution*, *Seattle Times*, *Bellingham Herald*, *Keene Sentinel*, and dozens of other newspapers across the country. The following is just a small sample of our coverage from 2015 and 2016. In addition to this sampling, every spring and fall, we publish and distribute issues of our own printed newsletter, *The Voice*. We also emailed issues of our e-news digest in 2015 and 2016.

Furor Over Drug Prices Puts Patient Advocacy Groups in Bind

The New York Times
September 27, 2016

US healthcare: Power to the patients?

Financial Times
May 23, 2016

Trump just dropped a big hint to the pharmaceutical industry

The Washington Post
November 14, 2016

Patients shouldn't be used as guinea pigs (Letter to the Editor)

Sun Sentinel
September 10, 2015

**Can War on Cancer Be Won?
A Surprising Answer**

Huffington Post (By Diana Zuckerman)
September 16, 2015

SPEEDING UP DRUG-APPROVAL PROCESS COULD HAVE DOWNSIDE

The Wall Street Journal
May 30, 2015

Why the FDA wants to ban tanning beds for minors

MarketWatch (WSJ)
December 22, 2015

Approved but not proven: what's up with FDA, cancer drugs?

Medscape Medical News
October 22, 2015

A Frenzy of Lobbying On 21st Century Cures

Kaiser Health News
November 28, 2016

Doctors Downplaying Drug's Suicide Risks Attract FDA's Scrutiny

Bloomberg
September 13, 2016

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