



NATIONAL CENTER FOR HEALTH RESEARCH

The Voice For Prevention, Treatment And Policy



Biennial Report 2018-2019



MESSAGE FROM THE PRESIDENT



In 2018 and 2019, we helped thousands of adults and children get the best possible medical treatment; we published articles and reports that will continue to help physicians provide better medical 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 helplines helped women, men, and children like you 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 all types illness and choose the safest and most effective treatments.
- ◆ Our groundbreaking study in *JAMA Internal Medicine* scrutinized 18 ineffective cancer drugs that are still being prescribed. We are informing doctors and patients 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.
- ◆ We persuaded Congress to protect all Americans' access to affordable health insurance, including those with pre-existing medical conditions.
- ◆ We trained researchers and journalists to better communicate the results of research on which treatments are best for which patients, and publicized important new study results.
- ◆ We urged the Food and Drug Administration (FDA) to require long-term studies of the safety and effectiveness for all medications, implants, and vaccines, so that consumers could make well-informed decisions for themselves and their children.
- ◆ We testified before the Consumer Product Safety Commission, urging them to ban chemicals in children's products and playgrounds that can cause early puberty, asthma, attention problems, and cancer.
- ◆ We urged city and state legislators to change laws that have resulted in lead and toxic chemicals in artificial turf and playgrounds, and responded to parents' requests for information.
- ◆ We testified before the FDA to ensure that medical treatments 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 educated legislators that innovative software and IT used in hospitals needs to be proven accurate and secure for all patients.
- ◆ We trained and continue to work with 100 patient advocates from across the country on how to make their voices heard to improve medical research on cancer treatments and prevention.
- ◆ We updated our free pre-breast cancer booklet (DCIS) and our free booklet for men about prostate cancer screening. We made both booklets widely available to patients and family members across the country.

Whether we were explaining well-established and complicated medical research information to families and health professionals, 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, consumers, policy makers, and the media.

Our research, training and educational efforts continue to represent the interests and needs of all the men, women, and children who are otherwise left out of 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.

Our Largest Program: The Cancer Prevention and Treatment Fund



Do Expensive Cancer Treatments Work Better?

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 or even begin to shrink, but ultimately the patient may not live even a day longer.

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, not realizing that there is no evidence of a meaningful health benefit. However, the FDA often requires that companies keep studying the drugs to find out if those medicines are actually extending lives.

Our Cancer Study

The Cancer Prevention and Treatment Fund published a study in *JAMA Internal Medicine* of 18 cancer drugs that had not been proven to help patients live longer. We found that only one was proven to improve quality of life. Two made quality of life worse, and the other 15 new cancer drugs either did not improve quality of life, or there is no research evidence to know if they do or not.

We were shocked that 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 (also called Cabometyx of 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 patients, Medicare, and insurers are still paying for them. When we asked FDA officials why they haven't rescinded the approval of ineffective cancer drugs, they stated that they still think those drugs might be effective. 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.

In other words, the FDA is approving cancer drugs on the basis of short-term, inconclusive data knowing that we may never know if those drugs truly are safe and effective or not.

We Need New Cures

Some physicians and patients believe the FDA blocks access to effective new cancer treatments. We disagree. We strongly support the FDA's "Expanded Access" program, which provides patients access to experimental drugs that have at least some evidence that they work.

The FDA protects patients by requiring well-designed clinical trials to provide evidence that a new cancer drug has benefits that outweigh the risks. Although the standards aren't as high as they should be, the FDA requires evidence that the patient has a good chance of benefitting at least in the short-term. The evidence has to show that the patient has a good chance of benefitting. In contrast, an experimental drug, no matter how "promising" is not proven to have benefits that outweigh the risks. It is still being studied, and it might not have been tested on more than a few patients.

Some patients are willing to take the chance on experimental drugs, but they should be told that they are experimental and they shouldn't have to pay for them. Experimental drugs should be provided for free by the company that makes them, because companies greatly benefit from information provided by patients in well-designed studies.

As shown in our study quoted above, even ineffective cancer drugs can cost well over \$100,000 per patient. The prices are usually much higher in the U.S. than other countries. In other words, U.S. patients are subsidizing the cost of cancer drugs in other countries. That isn't fair, and we're working with Congress to make cancer drugs more affordable.

Prevention

Cancer can be prevented, thanks to research proving which of your habits can reduce your chances of developing cancer or of cancer coming back after treatment.

Whether the research is on diet, exercise, smoking, vaping, radiation, carcinogens in artificial turf and

"Hopefully, every woman finds her way to your Web site. Your article has helped me arm myself with information I will need to select the right surgeon." —Annamaria Picollo, 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 of *The Dance of Anger**

playgrounds, or medications that can cause cancer, we're scrutinizing what is known and not known, and providing the information to you and to policy makers for free.

Working to Reduce Overtreatment of Breast Cancer

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 stage zero 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 a lumpectomy—a decision that may be 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 there are equally safe—and sometimes safer—alternatives available. CPTF is working with Congress, health professionals, and insurance companies 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.

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 often 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.

Prior to its release in 2018, we worked with award-winning filmmakers who created and disseminated *The Bleeding Edge*, a documentary about medical implants and other devices that have risks that aren't explained to patients or their physicians.

Training Researchers to Explain their Study Results

Researchers across the country are doing life-saving work, but it can take years for the results of those studies to change the practice of medicine. We're working to change that.

Companies that make drugs make sure

that the research results that they like get reported on TV, radio, newspapers, and social media. But when an important study shows that a popular treatment is not effective, or is harmful, who is going to pay a PR company to get the word out? Thanks to support from the Patient-Centered Outcome Research Institute (PCORI) we are helping researchers learn how to communicate their results in interesting, understandable ways to reporters, and training reporters to ask the right questions to determine the quality of new research findings and the implications for patients.

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, 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 6,000 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, most insurance companies consider surgical removal “medically necessary” for just a few complications, 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

"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

Environmental Health Issues

We continue to be a major voice fighting to ban dangerous chemicals, especially those that can cause obesity, cognitive damage, asthma, and cancer. Our current work to ban hormone-disrupting chemicals such as phthalates and BPA 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, and have been linked to birth defects in baby boys, including abnormal genitals, testicular cancer, and liver problems. We have fought well-funded, repeated efforts by industry to overturn the law since 2008, and are glad to report that those dangerous chemicals are still banned from children's products.

Originally developed as a synthetic estrogen that was replaced by an even more dangerous one, DES, **BPA** is currently used in hard plastic products and is 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 legislators in Maryland, Virginia, and Washington, D.C. Thanks to these efforts, companies have voluntarily stopped making baby bottles and infant formula cans with BPA.

Our efforts regarding BPA and phthalates is now focused on getting these dangerous chemicals removed from the packages used for foods,



including canned foods and beverages and frozen meals, and from artificial turf and children's playgrounds.

Keeping Families Safe

Too many chemicals used in our homes and communities can increase the risk of serious diseases including cancer. We explain to families and policy-makers how research proves why the cancer-causing chemicals in flame retardants used in drapes and furniture have risks that are much higher than benefits – for families and for firefighters.

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, adults at high risk of cancer, and others.

The founder of the University of Pittsburgh Cancer Institute, Dr. Ronald Herberman, warned his staff years ago that the risks from cell phone radiation raise concerns.

We know that most people are not going to stop using cell phones. Here are their recommendations on how to lower your exposure and your risks:

- ◆ Limit the 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 instead of talking (never while driving!)
- ◆ Avoid keeping your cell phone in your pocket, bra, or anywhere close to your body while it is turned on.

“Dr. Zuckerman’s pitch as it pertained to various health related issues was absolutely phenomenal. Her 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



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.

The Evidence is In: Obesity and Lack of Exercise Increase the Risk of Cancer, Heart Disease, and Early Death

Everyone knows about the obesity epidemic and its impact on diabetes, but did you know 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, colorectal cancer, and some other cancers.

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

In addition to our activities regarding BPA, phthalates, and artificial turf, described on page 6, the National Center for Health Research scrutinized new research to determine other potential causes of weight gain.

Obesity is caused by eating more calories than you burn up from physical activity, but some popular prescription medications drastically increase appetite and obesity. Some of the drugs that are especially likely to cause obesity are “atypical antipsychotics,” which are taken by more than 30 million Americans each year. These include Seroquel, Risperdal, Zyprexa, and Abilify.

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 or a year, so their health isn’t actually improved. 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. In 2019, we helped almost 3 times as many people as we did in 2014, and this number continues to grow. 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 provided one or more email responses to questions patients, family members, consumers, or health professionals have about preventing or treating specific types of cancer or other diseases, or provided free patient booklets or other materials that we had developed or adapted from the NIH or other credible websites.

We provide policy makers, 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.

“Thank you for being here and providing valuable information on your website. It was of great benefit

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 for patients, health professionals, policy makers, cancer researchers, and in the media.

As can be seen in the list of activities on page 9, we’ve interviewed on TV and in documentaries to 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 meetings. Other nonprofit organizations don’t participate in as many FDA meetings as we do. We are often the only public health speakers that challenge Big Pharma and other special interests.

We conduct research to improve medical treatments, and we publish the results in medical, public health, and policy journals.

In addition, we are fighting to:

- Improve the quality of care through studies that determine which treatments work best for which patients.
- Promote safer and more effective medical devices, such as cardiac implants, joint replacements, MRIs, and health IT software.

- Demand safer and more effective treatments for life-threatening diseases.
- Improve medical research that will result in better treatment options for all patients.

For several years, we’ve been on the forefront of efforts to ensure that medical products have been adequately tested and analyzed in **all kinds of patients** to determine safety and effectiveness for women and men, people of color, and children 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 and publishing research to document the lack of such data, and by meeting with decision makers at the FDA and Congress.

Despite our small size, we continue to be instrumental in organizing patients and organizations to fight for safer, more effective, and more affordable medical products. We are the major consumer voice on strengthening the standards for cancer treatments, to make sure they improve patient’s lives.

Breast Implants

We wrote a report explaining the well-documented evidence that breast implants cause symptoms known as “breast implant illness.” We also helped organize several meetings with patient advocates and FDA officials, which gave the patients the opportunity to tell FDA

officials about the anaplastic large cell lymphoma (ALCL) and other serious health problems they had developed because of their breast implants. As a result of these meetings and other work, the FDA held a public Advisory Committee meeting to discuss breast implant safety in March 2019. We testified about our research, which indicated that most women who had

developed serious health problems as a result of their breast implants recovered substantially or completely when their implants and scar capsules were surgically removed.

A few months later, FDA announced that Allergan would initiate a world-wide ban on their biocell textured breast implants, which are considered most likely to cause ALCL.

Meanwhile, we started a Breast Implant Working Group with two former presidents of the American Society of Plastic Surgeons, two patient advocates, and the president of the nonprofit Breast Cancer Action. Together, we developed a black box warning and Patient Informed Consent Check List, and urged the FDA to require both be made available to all potential implant patients. In October 2019, the FDA released a proposed guidance with a draft black box warning and check list. In December, we met with FDA officials to urge them to improve their draft.

MRI Contrast Agent

Many patients undergo numerous MRIs with contrast, in an effort to determine how best to treat their condition. MRIs can be life-saving; however, there is growing evidence that the contrast agents that contain gadolinium can accumulate in the patient’s brain or bones, causing serious health problems. In 2019, we completed a report on gadolinium to warn patients and their physicians about these risks.

Sunscreen

One way to prevent skin cancer is to wear sunscreen, and we want to make sure that sunscreens are safe and effective for you to use. We urged the FDA to study the active ingredients in sunscreen to make sure they are safe. The effects of different combinations of ingredients should also be researched, and we need conclusive evidence that sunscreens are safe for children, since this hasn’t been studied.



“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 organizations ensuring that FDA helps patients by approving cancer drugs that are proven safe and effective. We also work with other federal agencies to ensure that essential cancer research is conducted and that toxic chemicals and other products are removed from our homes and communities.

We do not accept funding from pharmaceutical companies, medical device companies, chemical companies, or other companies that make products that affect our health, making us one of the very few unbiased voices speaking on behalf of cancer prevention and treatment.

Here are examples of our efforts to educate policy makers, opinion leaders, researchers and the public in 2018 and 2019:

- ◆ Dr. Diana Zuckerman testified at the **Consumer Product Safety Commission** on their agenda and priorities for FY2019/2020, recommending action on toxic chemicals in children's and household products and artificial turf on fields and playgrounds, in April 2018.
- ◆ We provided four written recommendations to the **FDA** to improve the regulation of tobacco products including cigars, flavored tobacco products, and nicotine, in July 2018.
- ◆ Dr. Megan Polanin testified at an **FDA** Advisory Committee meeting about the approval of the "abuse-deterrent" opioid Remoxy (oxycodone), in June 2018.
- ◆ We provided two written recommendations to **EPA** concerning the review of toxic chemicals, in August 2018.
- ◆ We provided written recommendations to the **U.S. Preventive Services Task Force** regarding their research plan on screening for colorectal cancer, in January 2019.
- ◆ Dr. Stephanie Fox-Rawlings testified at an **FDA** Advisory Committee meeting on selinexor for relapsed refractory multiple myeloma, in February 2019.
- ◆ We provided recommendations to the **U.S. Preventive Services Task Force** on regarding guidelines for medications intended to reduce the risk for breast cancer, in February 2019.
- ◆ We provided recommendations to the **U.S. Preventive Services Task Force** regarding guidelines for risk assessment, genetic counseling, and genetic testing for BRCA, in March 2019.
- ◆ We provided recommendations to the **U.S. Preventive Services Task Force** regarding guidelines on screening for pancreatic cancer, in March 2019.
- ◆ Mr. Jack Mitchell testified before **Maryland State House Environmental Committee** on synthetic turf, in March 2019.
- ◆ Dr. Varuna Srinivasan testified at an **FDA** Advisory Committee meeting on evaluation of screening devices to detect high-risk HPV, in March 2019.
- ◆ Dr. Diana Zuckerman was an invited speaker at an **FDA** Advisory Committee meeting describing our study results of the health benefits when women remove breast implants that are causing health problems, in March 2019.
- ◆ Claudia Nunez-Eddy testified at an **FDA** Advisory Committee meeting regarding our project to assist women who need health insurance coverage for the medically necessary removal of breast implants, in March 2019.
- ◆ Dr. Diana Zuckerman testified at the **Consumer Product Safety Commission** on their agenda and priorities for FY2020/2021 recommending action on artificial turf on fields and playgrounds and organohalogen flame retardants, in May 2019.
- ◆ Dr. Diana Zuckerman moderated and spoke at community meetings in Washington, D.C. regarding toxic substances in playgrounds and artificial turf fields, in July 2019 and October 2019.
- ◆ Dr. Zuckerman testified before the **Washington, D.C. City Council** about the risks of artificial turf playing fields and children's playgrounds, in October, 2019.
- ◆ Claudia Nunez-Eddy testified at the **FDA** about a new contraceptive patch called Twirla from Agile Therapeutics. October, 2019.
- ◆ Dr. Zuckerman was a guest lecturer at **University of Maryland** courses, explaining the lack of clinical trials for medical devices and the possible risks of artificial turf and other products made with cancer-causing materials, in October, 2018 and November, 2019.
- ◆ Nina Zeldes testified at the **FDA** about Vernakalant for Rapid Conversion of Recent-Onset Atrial Fibrillation (Afib) on December, 2019.
- ◆ Dr. Stephanie Fox-Rawlings testified at the **FDA** about SABER-Bupivacaine (Posimir) for Post-Surgery Pain Relief on January, 2020.

COMMUNITY OUTREACH AND EDUCATION

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 or increase their chances of getting effective treatment. We also reach a broad virtual audience through social media on our Facebook page (www.facebook.com/nationalresearchcenter and www.facebook.com/CancerPreventionandTreatmentFund) and Twitter account (@NC4HR and @cancer_fund). At the end of 2019, we had thousands of Twitter followers and Facebook followers

Our online 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.

Community Meetings and Forums

Parents who had read our articles about the dangers of artificial turf playing fields and playgrounds have asked for our help. We've provided free help to families across the country.

People were shocked when we told them that the same kinds of toxic chemicals



"Our voices will get even stronger! Honored and privileged to have attended your Patient Advocacy workshop. Thank you Dr. Diana Zuckerman and staff, this was life changing." - Chandra De'Alessandro

that have been banned for more than a decade from children's toys are allowed in children's artificial turf playing fields and playgrounds. But many of these families hit a bureaucratic brick wall when they tried to convince officials from schools and city agencies to use safer, natural products.

We were surprised at how difficult it was to get these officials to listen to scientific evidence or even to common sense, and even more surprised to learn that families were installing artificial turf in their yards as well! We've testified in Washington, D.C., Maryland, and Connecticut about the risks of artificial turf and playgrounds and we've contacted officials in many other states. Our goal is to stop the installation of these fields before children are permanently harmed by frequent exposure to phthalates, VOCs, and other toxic materials.

Patient Training Workshops

Companies that make medical products are supporting many patient organizations, encouraging them to urge the FDA to approve treatments 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 2015, 2016, and 2017 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 continue to work with those patients and CPTF president Diana Zuckerman is an x-officio member of the **USA Patient Network Bond**.

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

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:



American Medical Student Association, American Medical Women's Association, Annie Appleseed Project, ASHES (Advocating Safety in Healthcare E-Sisters), Association for Medical Ethics (AME), Breast Cancer Action, Breast Cancer Consortium, Center for Medical Consumers, Connecticut Center for Patient Safety, Consumer Federation of America, Consumers Union, DES Action USA, Government Accountability Project, Institute for Ethics and Emerging Technology, Jacob's Institute of Women's Health, MedShadow.org, MISSD, National Consumers League, National Women's Health Network, Our Bodies Ourselves, The Society for Patient Centered Orthopedics, The TMJ Association, Union of Concerned Scientists, US PIRG, Washington Advocates for Patient Safety (WAPS), WomenHeart, and WoodyMatters.

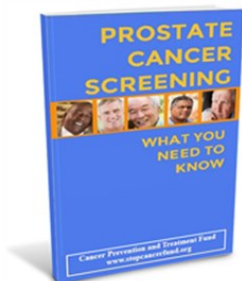
We hosted numerous coalition meetings, strategy sessions, and nationwide efforts to help consumers understand new health information in 2018 and 2019.

Free 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:

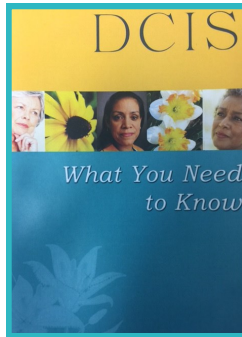
Prostate Cancer Screening: What You Need to Know. This 10-page booklet provides the information that men need to know to make informed decisions about if and when they should be screened for prostate cancer.

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.

Public Service Announcement with Actress Elisabeth Rohm

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

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.



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

Interns



John-Anthony Fraga, Alice Langford, and Elina Mir

The National Center for Health Research was assisted by more than 20 impressive interns in 2018 and 2019, including students from the University of Maryland College Park, George Washington University, UC Irvine, Brown University, Johns Hopkins University, University of Illinois Urbana-Champaign, University of Wisconsin-Madison, UC Berkeley, Yale, Tulane, King's College London, Northeastern, Providence College, and UT Southwestern.

Interns can focus on health communications, research, 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, and Hannah Kalvin

Janice Bilden Cancer Prevention Intern



Janice Bilden

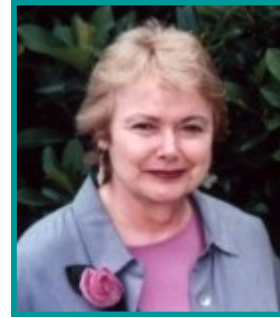
Claire Viscione is the Janice Bilden Cancer Prevention Intern. She is responsible for writing and updating web articles as well as spreading the word about cancer prevention on social media. She also assists with research and policy issues of importance to cancer prevention, including nutrition, exercise, other health habits, and avoiding dangerous exposures. Claire is currently completing her B.S. at the George Washington University, where she studies public health and business administration.

The Janice Bilden Cancer Prevention Internship was started in 2018 thanks to a generous donation from Janice's daughter, Holly Bilden-Stehling.



Claire Viscione

Marcy Gross Internship



Marcy Gross

Our 2018 Marcy Gross intern was Lauren Cronin. Cronin focused on public health and cell and molecular biology. Cronin was a part of the Public Health Society as well as the Women in Science Society at Tulane. She also was a member of the Alpha Phi Omega Service Fraternity and the Community Action Council of Tulane University.

Lauren graduated from Tulane University with a Bachelors in Science and Public Health in May 2018, and with a Masters of Epidemiology in 2019.

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 our work until her death in 2005.



Lauren Cronin

MEDIA AND COMMUNICATIONS

In 2018 and 2019, the media turned to the National Center for Health Research for timely, cancer-related 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. Dr. Zuckerman was 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 2018 and 2019. In addition to this sampling, every spring and fall, we publish and distribute issues of our own printed newsletter, *The Voice*. We also emailed monthly issues of our e-news Digests.

80,000 Deaths. 2 Million Injuries. It's Time for a Reckoning on Medical Devices

New York Times
May 4, 2019

More Than Half Of Surgical Stapler Malfunctions Went to Hidden FDA Database

Kaiser Health News
May 30, 2019

Breast Implants Linked to Rare Cancer Are Recalled

New York Times
July 24, 2019

Teens Hospitalized for Lung Damage After Vaping

Some Textured Implants Have a Cancer Risk: Here's Why Women Are Told Not to Remove

WJLA-TV
September 16, 2019

CONCERNS THAT PUBLIC HEARINGS ON BREAST IMPLANTS WILL FAVOR IMPLANT MANUFACTURERS

Fox and Friends
August 17, 2019

The FDA is Still Letting Doctors Implant Untested Devices into Our Bodies

Washington Post
January 4, 2019

E-CIGARETTES AFFECT A PERSON'S BLOOD VESSELS AFTER JUST ONE USE, STUDY FINDS

CBS News
August 22, 2019

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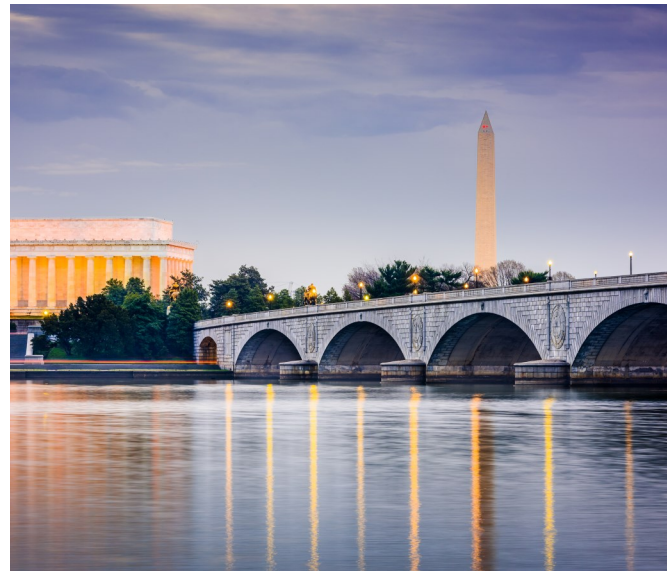
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