



NATIONAL CENTER FOR HEALTH RESEARCH

The Voice For Prevention, Treatment And Policy



Biennial Report 2020-2021



MESSAGE FROM THE PRESIDENT



In 2020 and 2021, 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 COVID-19, cancer, heart disease, diabetes, and other major diseases. Here's how:

- ◆ Our health helplines helped women, men, and children across the country. We helped people decide which diagnostic 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 of illness and choose the safest and most effective treatments.
- ◆ We scrutinized all the studies of COVID treatments, vaccines, and other prevention strategies, and made that unbiased information available to health professionals, patients, and journalists across the country.
- ◆ After our groundbreaking study in *JAMA Internal Medicine*
- scrutinized 18 ineffective cancer drugs that are still being prescribed, we continued to inform doctors and patients about those drugs. Only one was proven to improve quality of life, even though 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 also urged them to ban unsafe sleep products for infants and require safer home elevators.
- ◆ 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 community members' 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. These patients are often overlooked in clinical trials, and we advocated to change that.

- ◆ We continue to work with hundreds of patient advocates from across the country on how to make their voices heard to improve medical research on treatments and prevention.
- ◆ We made our free patient booklets widely available to cancer patients and family members around the world.

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 when 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.

FDA is Failing Cancer Patients

In April 2021, the FDA held a public Advisory Committee meeting on an unusual topic: What to do about cancer treatments that are not proven to work! The focus was on Keytruda, Opdivo, and Tecentriq. All 3 are cancer drugs that are proven to work for a small percentage of patients with some types of cancer, but were also granted "accelerated approval" for other types of

cancer for which the drugs were not proven to work. When drugs are granted accelerated approval, it is based on very preliminary data with the requirement that the companies do a better study to make sure the benefits of the drug for

that specific type of cancer outweigh the risks. These better studies showed that these 3 drugs were not proven to work for 6 different types of cancer, and yet they were still approved for them. That is costing patients and Medicare billions of dollars. As of August 2021, Opdivo is no longer approved for previously treated liver cancer, and Keytruda will no longer be approved for stomach cancer by the end of 2021, but the FDA had not rescinded other approvals for these 3 cancer drugs, despite the evidence that these treatments do not work, have serious risks, and cost a fortune.

Our Cancer Study

We 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 our study, the most expensive of the 18 cancer drugs was a thyroid cancer drug, Cometriq (also called Cabometyx) that

had no benefit for 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. 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.

"NCHR is a constant advocate for a safer healthcare system. I am so thankful for their commitment and their willingness to help me and so many others." - Sasha T.

*"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 self help books such as *The Dance of Anger* and *Why Won't You Apologize?**

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.

Unfortunately, even ineffective cancer drugs can cost well over \$250,000 per patient. The prices are usually much higher in the U.S. than in 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 all 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 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, because experts cannot always predict which new cancers will go away and which will become dangerous.

In addition, recent research shows that millions of women undergoing mastectomies for pre-cancer or early stage breast cancer (stages 0, 1, 2, and 3a) would live longer if they underwent lumpectomies instead.

Yet, as unbelievable as it may seem, medically unnecessary mastectomies have increased in the United States, not decreased. 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 safer alternatives available. We are 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.

Every year, the FDA reviews thousands of new diagnostic tests, im-

Our Work to Fight the COVID Pandemic

When the COVID-19 pandemic was announced in 2020, we immediately provided the best available information to the public, to health professionals, and to journalists. It was not easy – at the same time that we had to adjust to leaving our office and working from home, we were analyzing all the information that was publicly available, some of which was science based, but most of which was based on speculation, wishful thinking, or scientific guestimates.

There were four major ways that we were an important voice throughout the pandemic:

1. We provided free information in easy-to-understand summaries of what was known and what was not known about the virus: Who was most at risk, how to prevent getting infected or infecting others, which COVID tests were most accurate, and what treatments were proven to
2. We spent hours talking to journalists, who were justifiably confused about the conflicting information available. Fortunately, in July 2020 we received support from the Patient Centered Outcomes Research Institute (PCORI) that enabled us to host 9 teleconferences for reporters that featured unbiased experts who could explain some of the most confusing information about COVID. These teleconferences were attended by more than 180 journalists from across the country, enabling them to report information accurately to millions of Americans.
3. As information became available about the vaccines, we scrutinized the data and testified before the FDA and Centers for Disease Control and Prevention (CDC) about the
4. We published an article in the *American Journal of Public Health*, explaining how the criteria for “Emergency Use Authorizations,” which allowed COVID tests, treatments, masks, and vaccines to be sold in the U.S., were not as scientifically sound as the usual FDA standards for approval. We encouraged the FDA to switch to FDA approval standards as soon as possible.

Which Diagnostic Tests and Treatments are Best?

plants, 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.

We’ve worked with award-winning filmmakers who created and disseminated documentaries about medical implants and other devices that have risks that aren’t explained to patients or their physicians.

In 2021, *Explant*, a documentary about women who became seriously ill from breast implants, was released at the Tribeca film festival. In 2018, *The Bleeding Edge*, a documentary about other unsafe medical implants, was released at Tribeca and is still available on Netflix.

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 also pay experts to ensure that favorable research results 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 we are training reporters to ask the right

"I believe there is so much more that needs to be done to investigate all these items put into the body especially that we were told they were "safe"... Thanks for all your hard work and resources" -Christina P



questions to determine the quality of new research findings and the implications for patients.

In 2019 and 2021, we held 2 successful workshops for health reporters, teaching journalists about the nuances of research results, as well as training researchers to make their results understandable to reporters. Although the pandemic required us to postpone our second workshop from March 2020 to August 2021, the pandemic also resulted in the opportunity to host 9 monthly one-hour live online teleconferences on important COVID-related research issues, such as the risks to children, the initial research results for COVID vaccines, the research standards for Emergency Use Authorizations, variants, and other hot topics.

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 non-profit health policy and consumer community, and increasingly among health policy researchers and scholars.

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

As can be seen in the list of activities on pages 9-10, we influence policies, educate Members of Congress and their staff; publish in medical journals and on popular websites; and speak at dozens of public meetings. No other nonprofit organizations participate as close to that level; at many meetings, we are the only speaker advocating for patient safety.

In 2020 and 2021, the pandemic interfered with our usual schedule of in-person meetings on Capitol Hill as well as staff briefings. We expect that situation to improve in late 2021.

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 health care through studies that determine which treatments work best for which patients.
- Protect patients and protect the viability of Medicare by restricting the unsafe use of Aduhelm, a drug for Alzheimer's Disease that is not

proven to work but is proven to cause brain swelling.

- Improve the accuracy of genetic tests, cancer screening, and other diagnostics by reversing policies that have made it illegal for the FDA to ensure the accuracy of lab-developed in vitro diagnostic tests.
- 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, warning about Yaz, Yasmin, 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 aimed at strengthening FDA decision-making and protecting patients who rely on 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 **all kinds of patients** in order 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 non-profit organizations to fight for safer, more effective, and more affordable medical products, and is the major consumer voice on medical devices. We help non-

"I really appreciate all the work you have been doing for me and all the women."

-Priscilla D

profit organizations, consumers, and media who turn to us for unbiased information on a wide range of controversial topics. 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 all medical treatments, to make sure they improve patient's lives.

Helping Women Harmed By Breast Implants

We continue to be interviewed frequently about the well-documented evidence that breast implants can cause symptoms known as "breast implant illness." We helped organize several remote meetings with patient advocates and FDA officials, which gave the patients the opportunity to urge FDA officials to warn patients about breast implant associated anaplastic large cell lymphoma (BIA-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 is considering what information patients should be given about these risks.

In 2019, we started a Breast Implant Working Group with two former presidents of the American Society of Plastic Surgeons, patient advocates, and the president of the nonprofit Breast Cancer Action. In 2020 and 2021, we expanded our membership to also include a Board

member of Our Bodies Ourselves and the CEO of the data analysis group Device Events. 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. When the FDA released a proposed guidance with a draft black box warning and check list in 2019, we met with FDA officials to urge them to improve their draft in 2019, 2020, and 2021.

In addition to our work with the FDA, we continued to provide research-based information about breast implant illness and BIA-ALCL to patients and their advocates, and to the leadership of the American Society of Plastic Surgeons, including advice on how to improve the accuracy of information about breast implant risks on their website. We also reached out to the CDC to encourage them to add a billing code for breast implant illness and BIA-ALCL to enable patients to obtain insurance coverage.

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 it is sometimes possible thanks to the Affordable Care Act, which prevents exclusions due to pre-existing conditions. Nevertheless, most insurance companies rarely consider surgical removal "medically necessary," unless there is silicone leakage, chronic pain, or cancer caused by the implants. 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 the 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 heart disease and 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. In addition to making adolescence even more challenging, this could also increase the risk of breast cancer, prostate cancer, colorectal cancer, and some other cancers.

The National Center for Health Research is scrutinizing new research to determine the many 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 types of 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.



"I appreciate you validating my concerns and offering me your expertise and insight...Thank you so much! - Amanda G.

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 doesn't actually improve. We are urging the FDA to require long-term studies so that patients know whether or not these products will improve their health.

The risk of obesity may also 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. Learn more about these chemicals below.

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 many 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 it passed in 2008, and are glad to report that those dangerous chemicals are still banned from children's products.

BPA was 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 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 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 are 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.

We know that most people are not going to stop using cell phones, but you can lower your exposure and your risks by limiting the length of your calls; using

hands-free devices, "speaker phone," or holding the phone away from your ear; limiting your cell phone use in rural areas or anywhere reception is poor; text instead of talking; and do not keep your cell phone in your pocket, bra, or anywhere close to your body while it is turned on.

MRI Contrast Agent

Many patients undergo numerous MRIs with contrast, in an effort to determine if they have serious medical conditions. 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, and we have continued to educate patients about this in 2020 and 2021.

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. Given the growing evidence that some sunscreens contain dangerous chemicals, 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.



"I'd like to send my appreciation for the information you presented at the FDA Advisory Committee...I have been feeling overwhelmed and disheartened about the lack of dialogue and transparency in the last year and a half, and am grateful to you for acknowledging the importance of further investigation about benefits over risk/side effects, especially in that forum." -M.C.

Remember – We're Always Here for You!

We assist individuals from across the country through our online and telephone helplines. In 2020, we helped twice 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 patients and families, who are often left out of policy debates. We educate leaders in our nation's capital and across the country.

The National Center for Health Research is one of the most active organizations ensuring that FDA helps patients by approving medical treatments that are proven safe and effective. We also work with other federal agencies to ensure that essential 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.

In 2020 and 2021, NCHR staff testified at more than three dozen FDA Advisory Committee meetings about the safety and effectiveness of new medical products being considered for approval. A few examples of these testimonies include:

- ◆ January 2020: NCHR Senior Fellow Dr. Nina Zeldes testified about whether the extended release opioid Aximris is likely to be abused.
- ◆ January 2020: Dr. Nina Zeldes testified about the risks of combined Tramadol and Celecoxib for acute pain relief.
- ◆ February 2020: NCHR President Dr. Diana Zuckerman testified about evidence that talc in baby powder could be a carcinogen.
- ◆ February 2020: Dr. Diana Zuckerman testified about the negative side effects and lack of benefit for Cyramza for metastatic lung cancer.
- ◆ July 2020: NCHR Senior Fellow Dr. Meg Seymour testified about inadequate research on Belantamab Mafodotin as well as the risks for patients with relapsed or difficult-to-treat multiple myeloma.
- ◆ August 2020: Dr. Meg Seymour testified about how the evidence did not support the proposed use for Trelegy Ellipta for patients with chronic obstructive pulmonary disease.
- ◆ October 2020: Dr. Meg Seymour testified against claims that Amphetamine Sulfate immediate release oral capsules are "abuse deterrent."
- ◆ October 2020: Dr. Diana Zuckerman gave a presentation at an FDA Medical Devices User Fee Act meeting about the need for better safety standards.
- ◆ November 2020: Dr. Diana Zuckerman testified that evidence does not support the claim that Aducanumab (Aduhelm) is effective for treating Alzheimer's disease.
- ◆ December 2020: Dr. Diana Zuckerman testified about the need for better research to determine whether the Pfizer COVID-19 vaccine is proven safe and effective for all ages and races.
- ◆ December 2020: Dr. Diana Zuckerman testified about the need for better research to determine whether the Moderna COVID-19 vaccine is proven safe and effective for all ages and races.
- ◆ February 2021: Dr. Diana Zuckerman testified about whether the Johnson & Johnson COVID-19 vaccine is proven as safe and effective as the company had claimed.
- ◆ March 2021: Dr. Meg Seymour testified about the lack of evidence that Tanezumab is safer or more effective for osteoarthritis compared to over-the-counter pain medications.



- ◆ June 2021: Dr. Diana Zuckerman testified about the need for higher standards for wrist bands and other medical devices for nausea and related health problems.
- ◆ August 2021: Dr. Meg Seymour testified about the lack of evidence that TriGuard 3 is beneficial to patients and pointed out that is twice as likely to cause strokes and death.
- ◆ September 2021: Dr. Meg Seymour testified about the need for better data for COVID vaccine boosters.
- ◆ September 2021: Dr. Diana Zuckerman gave a presentation at an FDA Prescription Drug User Fees (PDUFA) meeting about the importance of improving “performance goals” for the legislation with additional safeguards for patients, such as enforcing the law requiring cancer drugs to be proven to work, and notifying patients immediately when drugs are found to be riskier than expected.
- ◆ September 2021: Dr. Diana Zuckerman gave a presentation at an FDA Medical Device User Fees (MDUFA) meeting about the importance of diversity in clinical trials for high-risk devices, and subgroup analyses conducted to make sure that the benefits outweigh the risks for major demographic groups and not only White men, such as women, Hispanics, and adults 65 and over.

We also testified about environmental health issues to the Environmental Protection Agency (EPA) and National Academies of Sciences, Engineering, and Mathematics (NASEM):

- ◆ December 2020: Dr. Meg Seymour testified about the risks of artificial turf at the plenary meeting for the **EPA's** Children's Health Protection Advisory Committee.

- ◆ April 2021: Dr. Meg Seymour testified regarding testing of the forever chemicals called PFAS at a **NASEM** meeting.

In addition to our oral testimonies, we provided written recommendations to various government agencies through 51 comments and letters between January 2020 and August 2021. Some examples include:

- ◆ January 2020: We provided recommendations to **FDA** about improving post-market safety studies of approved drugs and biological products.
- ◆ March 2020: We wrote a letter to the **Maryland House of Representatives** in support of Maryland House Bill to Ban State Funds for Artificial Turf and Playgrounds.
- ◆ April 2020: We provided recommendations to **FDA** about the need to improve healthcare providers’ understanding of opioids that are labeled as “abuse deterrent” even though they are addictive.
- ◆ May 2020: We provided recommendations to **FDA** regarding their guidance for industry recommending that they include more older adults in clinical trials for cancer treatments
- ◆ December 2020: We provided recommendations to **FDA** regarding the development of breast cancer treatments for premenopausal women.
- ◆ February 2021: We provided recommendations to the Agency for Healthcare Research and Quality (**AHRQ**) regarding their draft report to Congress on improving patient safety. We recommended that the report include warnings about potential risks caused by unproven treatments.
- ◆ March 2021: Dr. Diana Zuckerman wrote to the **Belvedere California City Council** to share information about the health risks of rubber playground surfaces.
- ◆ April 2021: We provided recommen-

dations to **AHRQ** to improve their draft report about breast reconstruction after mastectomy by including more information about long-term risks.

- ◆ July 2021: We initiated and wrote a letter co-signed signed by other scientific non-profits and that we sent to **HHS Inspector General, CMS, and key members of Congress** regarding the FDA’s unscientific and inappropriate approval of Aduhelm for Alzheimer’s disease.
- ◆ August 2021: We provided recommendations to **FDA** on notifying patients and healthcare professionals about the materials used in medical devices, to help reduce allergic reactions and similar problems.
- ◆ September 2021: We submitted recommendations to **Medicare and Medicaid** in support of continued funding of telehealth services for mental health.

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 pages www.facebook.com/nationalresearchcenter and www.facebook.com/CancerPreventionandTreatmentFund; Twitter accounts: @NC4HR and @cancer_fund; and Instagram accounts: @safe.to.play and @comicrelief_nchr. We have thousands of Twitter and Facebook followers.

Our online hotlines enable anyone to obtain free information about their own health personal concerns by contacting info@center4research.org 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 that have been banned for more than a decade from children's toys are allowed in children's artificial turf playing fields

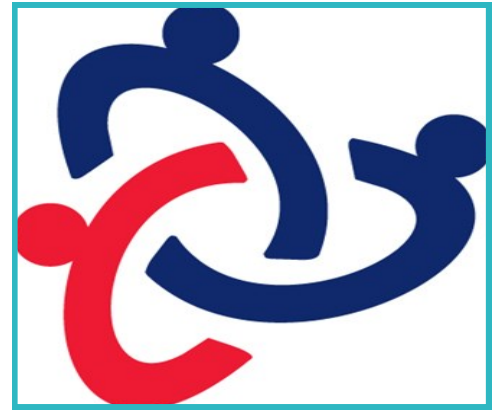
and playgrounds. But many of these families hit a bureaucratic brick wall when they tried to convince officials from schools and city agencies to use safer, natural products.

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, New York, and Connecticut about the risks of artificial turf and playgrounds and we've contacted officials in other states as well. Our goal is to stop the installation of these fields before children are permanently harmed by frequent exposure to phthalates, volatile organic compounds (VOCs), lead, and other toxic materials.

Training Journalists to Provide Accurate Medical Information

The news media and social media are major sources of information regarding health issues, whether it is the 24/7 news cycle on COVID or new research on cancer, heart disease, pain management, diabetes, or other serious health issues. With partial support from the Patient Centered Outcomes Research Institute (PCORI), we hosted free workshops, teleconferences, and webinars for reporters in 2019-2021. The in-person workshops and several teleconferences and webinars were aimed at improving journalists' understanding of important new research results on a wide range of health topics. As noted earlier in this report, nine of the teleconferences were focused on research information about the spread of COVID and possible treatments and vaccines, as new research information became available in 2020 and 2021.

We are proud that this work was enthusiastically appreciated by almost 200 journalists across the country, who used the information we provided as they disseminated



USA Patient Network

life-saving information via TV news, newspaper and magazine articles, websites, and other media.

Patient Training Workshops

Companies that make medical products financially support many patient organizations, encouraging them to urge Congress and the FDA to approve treatments more quickly. However, those patient groups have rarely focused on safety issues, or on other outcomes important to patients.

After hosting free workshops in 2015, 2016, and 2017 to train patient advocates about research on the safety and effectiveness of drugs and medical devices, our 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. Many of these patient advocates have now testified at public meetings with the FDA and other government agencies to improve the safety and effectiveness of medical products, and to improve the safety information available to patients and their family members. We continue to work with those patients and NCHR president Diana Zuckerman is an x-officio member of the **USA Patient Network** Board.

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.

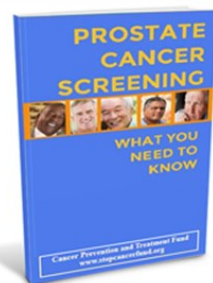
Through this coalition, we host numerous coalition meetings, strategy sessions, and nationwide efforts to help consumers understand new health information. The coalition also presents oral testimony and written comments to federal agencies.

For example, in September 2021, Dr. Thomas Eagen, NCHR's Health Policy Director, spoke on behalf of numerous coalition members at an FDA meeting about the importance of diversity in clinical trials and ensuring that information about the risks of devices are accessible to all adults.

Free Patient Booklets

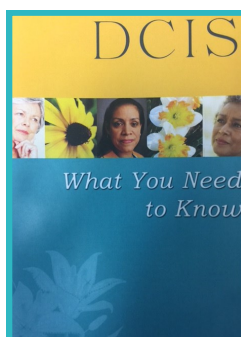
We continued to distribute electronic and hard copies of the following patient booklets, which have been updated as important new research results are made available:

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 for free on the National Center for Health Research website and our 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 for free on our 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 more than 1,500 free hard copies of this 32-page color booklet to medical centers, physicians, and individuals.



It is also available for free on the on the National Center for Health Research website and our 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 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 to 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.



Internships



Alea Sabry and Edyth Dwyer, Summer 2021

The National Center for Health Research was assisted by 17 impressive interns in 2020 and 2021, including graduate and undergraduate students from Brown University, Cornell University, Duke University, Georgetown University, George Washington University, Konyang University, UC Berkeley, University of Miami, University of Michigan, University of Notre Dame, University of Texas Southwestern Medical Center, University of Virginia, and University of Wisconsin-Madison.

Interns can focus on health communication or policy and gain a wide range of experiences working with Capitol Hill. Interns learn about the Washington, D.C. policy scene while helping to communicate with the public about a range of health issues. The pandemic required us to switch to remote internships in 2020, but we were able to offer hybrid (remote + in-person) internships in the summer and fall of 2021. 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 (when in-person hearings were still open to the public!)



Janice Bilden

Janice Bilden Cancer Prevention Intern

The Janice Bilden Cancer Prevention Interns are responsible for writing and updating web articles as well spreading the word about cancer prevention on social media. They also assist with research and policy issues of importance to cancer prevention, including nutrition, exercise, other health habits, and avoiding dangerous exposures.

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



Jack Mitchell

Jack Mitchell Health Policy Internship

We were devastated when our Director of Health Policy, Jack Mitchell, died from non-Hodgkin's lymphoma in December 2019. Jack started his career as a muckraking journalist working for

columnist Jack Anderson, became a Washington correspondent for CNN, and became a federal investigator for the US Senate and the FDA, where he was a special assistant to Commissioner David A. Kessler. Their crusading effort to regulate tobacco companies culminated in a 2000 Supreme Court case and the subsequent regulation of tobacco products by the FDA. We are honored to offer the Jack Mitchell Policy Internship, which is generously supported by his family, friends, and colleagues.



Omega Logan Silva

Omega Logan Silva Internship

It is with great sadness that we report the passing of Dr. Omega Logan Silva, one of our long-time Board members. Dr. Silva was professor emeritus of medicine at the George Washington University in Washington, D.C. She was a long-standing advocate for universal health care and a committed supporter of NCHR and of the advancement of women in medicine. In 1963, she returned to Howard University to train as a physician, earning her medical degree in 1967. She served as president of the American Medical Women's Association, served on 6 different advisory groups for the NIH, and received numerous awards as well as letters of commendation from President Reagan and President Clinton.

The Omega Logan Silva internship is generously supported by her friends and family, and focuses on women's health and training women in medicine.

MEDIA AND COMMUNICATIONS

In 2020 and 2021, 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. The following is just a small sample of news stories that quoted us in 2020 and 2021. In addition, we publish and distribute issues of our own printed newsletter, *The Voice*, and emailed monthly issues of our e-news Digests.

New Alzheimer's drug could be 'devastating' for Medicare

Politico
June 15, 2021

FDA Panel to Lay Regulatory Groundwork for COVID-19 Vaccine

NPR
October 22, 2020

7 things to know about bad COVID-19 tests

CBS 5
July 29, 2021

How the Coronavirus Pandemic May Affect Cancer Clinical Trials

Cancer Therapy Advisor
September 23, 2020

Public Health Experts Want Rigorous FDA Review of COVID vaccine data

First, Their Breast Implants Made Them Sick. Then They Were Hit with the Bill.

Cosmopolitan
August 18, 2020

COVID-19: FDA SET TO GRANT FULL APPROVAL TO PFIZER VACCINE WITHOUT PUBLIC DISCUSSION OF DATA

Politico
August 7, 2020

What Genentech is doing to fix biotech's diversity problem

Fortune
April 7, 2021

How FAUCI AND THE NIH GOT AHEAD OF THE FDA AND CDC IN BACKING BOOSTERS

LA Times and CNN.com
September 16, 2021

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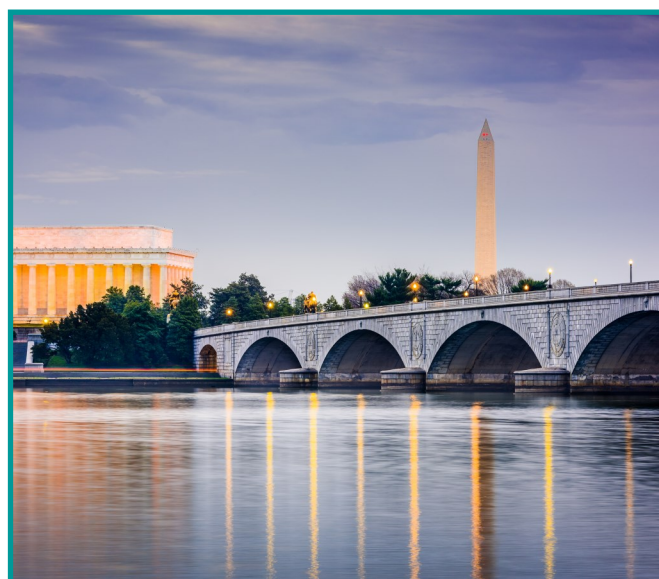
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Harriet Lerner, Ph.D.
Psychologist and Author

Lisa Lopez, J.D.
Former Senior Vice President and General Counsel
for Haemonetics Corporation



We are very sad to report that two of our wonderful, long time board members passed away in 2020:

Mary G. Hager, M.A.
Freelance Writer
Omega Logan Silva, M.D.
Professor Emeritus,
George Washington University

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