National Center for Health Research

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

The Cancer Prevention and Treatment Fund

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

Cancer Helpline:
info@stopcancerfund.org

Websites:
www.center4research.org
www.stopcancerfund.org

Actress Elisabeth Rohm Joins our Fight Against Cancer

It can be easy to forget that actors and actresses are real people with hopes and concerns just like ours. They seem to live in a totally different world on a totally different planet – planet Hollywood to be exact. But they are mothers, fathers, sons, daughters – and they care about their health and the health of their friends and loved ones.

So we were thrilled but not surprised when Elisabeth Rohm enthusiastically agreed to film a public service announcement (PSA) for the Cancer Prevention and Treatment Fund. The timing was challenging – she was about to leave town to start filming two different movies. So we were especially grateful that she was willing to film our PSA the day before she left.

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

While Elisabeth is a dedicated mother and down-to-earth human being, she is also in a unique position as a TV and film actress. She’s been in TV shows such as Law and Order, Hawaii Five-O, and The Last Ship, and in many films, including starring alongside Jennifer Lawrence in American Hustle and Joy. We are so lucky that she wants to use her fame and recognition for our cause!

Thanks also to the wonderful director Gigi Gaston of Flying Turtle Films and Anastasia Roussel of White Swan Films.

The PSA went up on our website just before Thanksgiving. We hope it will soon also be on TV and radio. ♦
Board of Directors

George Thomas Beall
Former Managing Director
Ogilby Public Relations

Sarah Deutsch, JD
Counsel, Mayer Brown

Ben Gitterman, MD
Associate Clinical Professor
Pediatrics and Public Health
George Washington University

Mary G. Hager, MA

Nancy Hardt, MD
Retired Professor and Associate Dean University of Florida College of Medicine

Judith L. Harris, JD
Partner, Reed Smith

Courtney McKeldin
Retired Commissioner, Baltimore City Zoning Board

Alan Mendelson, LLC
Axion Venture Partners

Omega Logan Silva, MD
Former President, American Medical Women’s Association

Duchy Trachtenberg
Former Councilmember
Montgomery County, MD

Susan F. Wood, PhD
Associate Professor
George Washington University

Diana Zuckerman, PhD
President
Nat’l Center for Health Research

We can’t be bought.

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

Lawmakers Try for Year-End Bill on Medical Research, Devices and Opioid Addiction

The Wall Street Journal
November 26, 2016

Anthem declines to cover Sarepta drug for Duchenne, citing doubts over data

STAT News
October 7, 2016

Bullying Harms Victims and Perpetrators of All Ages

Diana Zuckerman, Health Progress
July/August 2016

Congress has been working on bills to speed up drug approvals at the FDA, but we’re worried this puts patients at risk of using unsafe or ineffective medical products. These bills would allow the FDA to approve drugs and devices based on “well-educated guesses that a treatment works, rather than scientific evidence of real benefits such as living longer or having fewer complications,” wrote NCHR President, Dr. Diana Zuckerman, in her article in the Chicago Tribune, Baltimore Sun, Sacramento Bee, and other newspapers across the country.

We all deserve better than untested “snake oil” treatments. We also expressed our concerns on NPR and in a blog in Health Affairs and when quoted in STAT News, HealthZette, Health News Review, Wall Street Journal, and American Health Line.

There are many issues that can cause people to urinate frequently, but is an “overactive bladder” just a name coined by drug companies to sell treatments that don’t actually work well? We told MedPage and the Milwaukee Journal Sentinel that people need to carefully consider the minor benefits compared to the risks of these drugs, such as tooth loss due to dry mouth.

Mylan, the company that makes EpiPens, has raised prices by 600% while working behind the scenes to prevent less expensive competition. Mylan paid for research against a generic EpiPen designed to “prove” it would fail 93% of the time. Dr. Zuckerman told NBC New York and NBC San Diego that “the study was just flawed from start to finish.”

As we move into a Trump presidency, everyone is wondering about his plan for healthcare. “I think the honest answer is nobody knows” what to expect, Dr. Zuckerman told the Washington Post. We told MedPage Today it’s unclear what will happen to Obamacare.

FDA approved a drug for Duchenne’s Muscular Dystrophy despite no conclusive evidence that it actually works. Dr. Zuckerman told the New York Times and Tech Times that FDA “has set a dangerous precedent. To prove something works, you have to compare it to something else – a placebo or a treatment. They didn’t do that.” There’s no telling what other drugs FDA will approve on similarly skimpy evidence, she told the Washington Post, Kaiser Health News and STAT news.

The drug company is selling the drug for $300,000, and Anthem has already announced they will not be covering it because of doubts about whether it works. Dr. Zuckerman told STAT and Reuters that “the FDA is not doing patients any favors when they approve a drug or device that is not proven to work. To keep health insurance affordable, companies need to ensure that they are paying for safe and effective treatments.”

Bullying should not be considered an acceptable part of growing up (or the workplace!). In an article published in the Catholic Health Association’s magazine Health Progress, Dr. Diana Zuckerman explains how bullying can harm both victim and perpetrator regardless of age.

Many patient groups lobby Congress and FDA to approve medical products, but they’re often influenced by pharmaceutical companies. As a result, they tend to be silent on issues when it comes to drug pricing. “I’ve found almost none that are focused on the public health issues of affordable health care, affordable insurance, or a sustainable system,” Dr. Zuckerman told The New York Times.

Our Center joined several other groups to urge Ikea to recall a dresser that has tipped over and killed three children. In response, we’re happy to report that Ikea issued a recall on the dressers! We told Fortune and Consumer Reports that consumers weren’t adequately warned of the risks.

Anthem declines to cover Sarepta drug for Duchenne, citing doubts over data

STAT News
October 7, 2016

Trump just dropped a big hint to the pharmaceutical industry

Washington Post
November 14, 2016

21st Century Cures Act: Yes or No? No: Act’s promise of quick cures is a brew of ultra-hype mixed with snake oil

Diana Zuckerman, Chicago Tribune
July 21, 2016

We’re in the Headlines!
Why do so many cancer patients get treated with drugs that don’t work?

Most of us know cancer patients who received drugs that drained their energy and joy of living, but didn’t seem to benefit them. In some cases, the cancer stopped growing or even started to shrink, but ultimately the patient did not seem to live even a day longer.

Why is that?

A key problem is that cancer drugs do not have to be proven to prolong anyone’s life in order for the Food and Drug Administration (FDA) to approve them. Researchers at the National Cancer Institute and Oregon Health & Science University reviewed all the cancer drugs approved by the FDA from 2008 to 2012. They found that two-thirds were not required to be proven to prolong or save lives, but instead were approved based on “signs” such as tumor shrinkage over a relatively short period of time.

Once the drugs were approved, thousands of patients started taking them and paying for them, despite the lack of evidence of a meaningful benefit. However, the FDA did require the companies to keep studying the drugs to find out if they actually helped people live longer.

The answer, unfortunately, is that only five of the 36 drugs were proven to help patients live longer. Eighteen drugs (50%) failed to extend life and 13 (36%) have an unknown impact on survival because data on them are not available to the public. Since companies are very good at sharing information when their drugs are proven effective, experts assume that means those 13 drugs are not proven to work.

Our Center just published a new study in JAMA Internal Medicine, looking more carefully at those drugs. We found that most did not improve quality of life either. This is not surprising, since cancer drugs so often cause nausea, vomiting, hair loss, and exhaustion. We also looked at the cost of those cancer drugs and found something that patients, doctors, and lawmakers need to know: new cancer drugs that are not proven to work cost just as much as the ones that are effective – up to $170,000 per patient.

Meanwhile, the ineffective cancer drugs remain on the market, and Medicare and insurers are still paying for them.
Honoring Foremothers and Health Policy Heroes

Although we often hear of the impressive accomplishments of our Forefathers, we rarely hear about Foremothers. With ABC 7 News anchor Maureen Bunyan as our wonderful emcee, we honored Democratic Leader Nancy Pelosi, journalist Judy Woodruff, and Civil Rights champion Elaine Jones as trailblazing “Foremothers” and two heroes from Flint, Michigan as Health Policy Heroes at our annual Awards Luncheon at the Mayflower Hotel.

To celebrate Mother’s Day, the Foremother awards honor lifetime achievements by women who have broken down barriers for other women and whose inspiring contributions helped improve the lives of adults and children nationally. The Health Policy Hero awards are for recent extraordinary contributions that directly improve the health and safety of adults and children across the country.

“We’re thrilled to honor LeeAnne Walters and Marc Edwards, two of the most important voices fighting the public health crisis caused by unsafe drinking water in Flint, Michigan and many other communities,” said NCHR president Dr. Diana Zuckerman. “And these three Foremothers have inspired millions of women and opened up a world of opportunities for others. I’m so proud to have the opportunity to honor them.”

Foremother Nancy Pelosi is the most powerful woman in Congress and our nation’s first woman Speaker of the House. Wendell Primus, Leader Pelosi’s Senior Policy Advisor, accepted her award.

“I think she would describe her proudest moment as when the Affordable Care Act was passed,” Mr. Primus said during the ceremony. “More than anything else, I think Nancy Pelosi understood how important this bill was, and she equated it to social security, Medicare, and Medicaid.” “If it wasn’t for her toughness during that period of time, it never would’ve happened.” Besides toughness, he spoke about her “graciousness” and “optimism” as her defining qualities.

Foremother Judy Woodruff is one of our nation’s foremost journalists. She was one of the few women serving as a White House correspondent during the Carter Administration and has been in the top ranks of journalists ever since – at CBS, NBC, PBS, and CNN. She co-founded the International Women’s Media Foundation to help mentor and encourage other female journalists to succeed worldwide.

During the luncheon, Judy Woodruff thanked the women journalists like Marguerite Higgins (WWII correspondent), Helen Thomas, and Barbara Walters who paved the way for her. Because of these heroes, Ms. Woodruff said that “by the time I graduated college and began to look for a job in journalism — this was in the late 1960’s — there were still barriers, but there was beginning to be a grudging acceptance that women might have to be put up with.” She went on to say, triumphantly, that “Gwen Ifill and I are, today, the first two women to co-anchor a national television newscast.” Sadly, Gwen Ifill died of cancer six months later.

Foremother Elaine Jones has dedicated her life to the Civil Rights Movement. She has been an inspiring champion for fairness and equality, successfully fighting for voting rights and against discrimination as the first woman to serve as the President and Director-Counsel of NAACP’s Legal Defense Fund.

During the awards ceremony, Ms. Jones spoke about her time as special assistant to the U.S. Secretary of Transportation in the 1970’s. She went to the head of the Coast Guard and asked, “Why is it that women are not admitted to the Coast Guard Academy?” When she found out there was no law prohibiting this, she declared, “We need to work on this and get this done.” However, as she pushed to include women in the Coast Guard Academy, she was told that “the wives are concerned that the men will look up the skirts of the women,” to which she replied, “Oh, that’s not a problem, just change the dress code and put the women in pants!” Eventually, they took her advice and admitted women into the Coast Guard Academy (with a new dress code).
Leaving a Legacy

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

For more information, contact us at info@center4research.org.

Health Policy Hero Marc Edwards is the Virginia Tech engineer and MacArthur “genius” award winner who was named one of Time’s 100 Most Influential People of 2016. He has spent hundreds of thousands of dollars of his own money to get to the truth about water safety in Flint; Washington, D.C.; and other communities.

However, during his speech at the luncheon, he mostly focused on Ms. Walter’s accomplishments. He said he often tells his students, “The most powerful force in the universe is a mother concerned about the health of her children. [But] what I think makes LeeAnne so extraordinary is how she exemplifies the heroism of all Flint residents because after her kids were protected, LeeAnne kept fighting for the health of every other child in Flint.”

LeeAnne Walters is a “stay-at-home” Mom who realized that state and local officials were not telling the truth about the water in Flint. She conducted her own investigation and was instrumental in getting Mr. Edwards and the EPA involved. “It’s still really weird for me for people to say ‘hero’ because we were just doing the right thing,” she explained.

Marcy Gross Intern: Mingxin “Mandy” Chen, MHS

Mingxin “Mandy” Chen joined the NCHR team in September as a Marcy Gross intern and will soon be a public health Fellow. She graduated from Johns Hopkins Bloomberg School of Public Health in May 2016 with a Master of Health Science in Health Economics. She previously studied Microbiology and Applied Statistics at Colorado State University in Fort Collins. Mandy is passionate about making high-quality health care more affordable and applying her expertise in health economics and quantitative analysis skills to improve the well-being of others.

Marcy Gross was a nationally respected health policy expert, specializing in women’s health. While at NCHR, Mandy helps translate research findings into something understandable for the general public. She believes information about scientific discoveries should be more accessible in order for the public to make informed decisions. One of her current projects involves studying how safe and effective new FDA-approved drugs are for different genders, ages, and racial groups.

Fun Fact: She can write traditional Chinese calligraphy!

Ruth Nadel Intern: Natalie Rosseau, BA

Natalie worked with us in the summer and became our Ruth Nadel intern in the fall. She’s originally from Chicago and recently graduated Phi Beta Kappa from Cornell University with a Bachelors of Arts in History, with minors in Law & Society and Inequality Studies. She’s most interested in learning about health disparities and the Affordable Care Act.

Ruth Nadel was a staunch advocate for women’s health issues – many of the same issues that Natalie is working on at NCHR. One of Natalie’s major projects is ensuring women’s access to medically necessary procedures, as well as collecting data and analyzing health insurance plans as a part of the NCHR Affordable Care Act project.

Natalie is passionate about providing patient-centered and culturally competent clinical care, as well as the intersection between health and policy, and health disparities. She will start medical school in August 2017. Natalie hopes to combine her enthusiasm for history and languages with her passion for medicine into a career that will include clinical practice, global health, and health policy.

Fun Fact: She’s fluent in French!

Thank you to our interns: our Secret to Success!

Do E-cigarettes Do More Harm than Good?

Quitting smoking is very difficult, so it’s no wonder that smokers search for strategies that can help them quit, or at least replace smoking. Many people have turned to electronic cigarettes, or e-cigarettes, which heat a liquid cartridge and deliver flavored nicotine through a smokeless vapor.

The key question is: is vaping safer than smoking?

Although e-cigarettes are advertised as the cleaner way to smoke, the vapor contains many toxic and cancer-causing chemicals. The ingredients are similar to those used in embalming fluid and paint thinner, and include heavy metals like nickel and lead that have been banned from paint because of the many health risks. So why are these allowed in e-cigarettes?

The reason: e-cigarettes were not regulated when they were first sold. It wasn’t until this year that the FDA gained the authority to regulate e-cigarettes. FDA’s new regulatory authority means that by 2018, all packaging for e-cigarettes must contain the following warning: “WARNING: This product contains nicotine. Nicotine is an addictive chemical.” It also means that children are no longer able to purchase e-cigarettes— the age limit is 18 years or older, just like other tobacco products.

The age requirement, which went into effect in August, is especially important given the rise in e-cigarette use among children and teens. More than 3 million students in middle school and high school were reported e-cigarette users in 2015, and this is increasing year after year. Less than 2% of high school and middle school students used e-cigarettes in 2011, but this rose to 16% of high school students and 5% of middle school students in 2015. Since e-cigarettes come in flavors like bubble gum and watermelon, they are obviously intended to appeal to youth. And it works: children and teenagers are more likely to try vaping because they mistakenly think it is safe. This just leads to more children and teens addicted to nicotine.

Many state and local governments are banning e-cigarette use in places where traditional tobacco smoking is already prohibited. These states include California, Connecticut, Delaware, Hawaii, Maine, New Jersey, North Dakota, Oregon, and Utah. Our Center is actively supporting these efforts to restrict use of e-cigarettes in public, as the health effects and effects of secondhand vapor inhalation are still being studied and unknown.

It is important to know that there is no research that suggests that e-cigarettes help to quit smoking. In fact, the amount of nicotine that is inhaled through e-cigarettes varies greatly, meaning that you might actually be taking in more nicotine than you were from smoking, and therefore increase, not decrease, your addiction.

In addition to the dangers of vaping, nicotine cartridges left around the house have harmed children and pets. For example, the number of calls to poison control centers for children who were poisoned by e-cigarette cartridges increased from 271 calls in 2011 to 3,783 calls in 2014. It is estimated that a call is made to a poison control center somewhere in the country about a young child exposed to e-cigarette cartridges about 7 times every day. It only takes a few drops of the liquid to result in a trip to the emergency room, and depending on the concentration and time to treatment, these poisonings can be lethal. Typical symptoms are nausea, vomiting, increased heart rate/blood pressure, and seizures.

There are many strategies proven to help people quit smoking. E-cigarettes are not one of them.

Although e-cigarettes are advertised as the cleaner way to smoke, the vapor contains many toxic and cancer-causing chemicals.
More than 62,000 people will be newly diagnosed with thyroid cancer this year, and the number is growing. There is a lot of debate about whether the disease is becoming more common, or if the increased rates of diagnosis are due to more people being screened and diagnosed based on ambiguous findings that might not ever become harmful.

That might sound odd, because most people think the best way to beat cancer is to get diagnosed and treated early. But in recent years there is a growing awareness that some conditions that have been called cancers are so slow growing that they are not really dangerous. Examples include some forms of prostate cancer, ductal carcinoma in situ (DCIS) in the breast, and now thyroid cancer.

What makes the issue even more difficult is that children and adults of any age can be diagnosed with thyroid cancer. Most are between the ages of 20 and 55, which is younger than many types of cancer. What parent wouldn’t want their child to be treated for something called cancer? And yet, treatment may not be the best course of action, because the treatment itself can cause harm to those children or young adults for the rest of their lives.

Research is being conducted to determine who is most likely to benefit from screening, diagnosis, and treatment. But until those studies are completed and those questions are answered, doctors and patients need to decide what to do. That means that doctors need to figure out how to best talk to patients and not unnecessarily scare them if they are diagnosed with thyroid cancer. This can help prevent patients from getting a treatment they don’t need that will almost certainly harm as opposed to help.

Thanks to a “Pipeline to Proposals” award from the Patient Centered Outcomes Research Institute (PCORI), an independent, non-profit research institution, our Cancer Prevention and Treatment Fund is planning a meeting of thyroid cancer patients, doctors, and researchers to discuss how best to improve doctor-patient conversations about thyroid cancer. Our new Senior Fellow, Christine Skubisz, PhD and president Diana Zuckerman, PhD are directing the project, partnering with Gary Bloom, the Executive Director of ThyCa, the Thyroid Cancer Survivors’ Association.

...treatment may not be the best course of action, because it can cause harm to [some] children or young adults for the rest of their lives.

Help us hold down the fort!

With this changing and uncertain political climate, we promise to continue fighting for you and the health of your family and friends. That means making sure that:

- The chemicals used in products in your home and community are safe,
- The benefits of medical products outweigh the risks and doctors and patients are giving accurate information about risks and benefits,
- Pharmaceutical and device companies do not mislead you!

This is a very challenging time. We’re holding down the fort, and we need your help to do it. Please consider giving to us today -- your donation means more now than ever.

Thank you in advance for considering a donation to support our work. It will help us continue to assist patients and family members every day. Just visit www.stopcancerfund.org or www.center4research.org and click the donate button on the home page, or donate through CFC# 11967.

Thank you!
What does Elisabeth Rohm (pictured above with Jennifer Lawrence in the movie American Hustle) have to do with our Cancer Prevention and Treatment Fund? Find out on Page 1!