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

Workshop Brings Patient Advocates Together

Should research on medical treatments be “patient-centered?” The answer seems obvious, but for decades doctors and researchers designed studies to figure out which treatments worked best without asking patients what outcomes mattered to them.

That’s changing, and now researchers from all over the country are saying they want patients to be more involved in research decisions.

Nowhere is that more obvious than on Capitol Hill, where pharmaceutical and medical device companies are training patients to lobby for “faster cures.”

Patients without treatment options want and need cures as soon as possible, but most patients want safer and more effective treatments. Our goal is to reach out to all patients to make sure they have the training and confidence they need to express their views to researchers.

On November 13-14, we held our second Patient Advocacy Workshop, to train patients and family members from around the country. They came together in shared solidarity to learn about the way research is conducted, to learn which treatments are best for which patients, and to learn about the roles of the Food and Drug Administration (FDA) and National Institutes of Health (NIH), and other federal agencies whose decisions will affect the lives of millions of patients.

We kept the workshop small (just 31 patients) so that everyone could be actively engaged. Here’s just a few of the patients who participated:

Sandra Rice, lost her sister and cousin to breast cancer in their 30s, so she was very diligent about screening. Her primary care physician and breast specialist helped her catch her own cancer early. She kept a positive attitude and before undergoing chemotherapy, Sandra’s daughter picked a color to dye her hair (shown above) and her friends helped to name her wigs Beatrice and Chloe.

Sandra wants to help patients make informed decisions about their medical care, and believes that improving clinical trials and making sure that African-Americans are included in those studies is essential. “I want to make sure that every patient and family has a clear understanding of the risks and benefits of medical research and the type of research that is used to make decisions about medications” she says.

Robert Wright had a very aggressive form of prostate cancer that was linked to his Agent Orange exposure as a combat medic in Vietnam. “I made a deal with God to keep me well enough to help other men,” and Robert has kept his end of the bargain.
**We’re in the Headlines!**

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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.

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**Politicians want to speed up drug approvals. That could backfire.**

*Washington Post*  
November 24, 2015

**Letter to the Editor: “Patients shouldn’t be used as guinea pigs”**

*The Sun Sentinel*  
September 10, 2015

**FDA revisits safety of the Essure contraceptive device**

*NPR*  
September 21, 2015

**Psst! Industry Has Taken over FDA**

*Medical Device and Diagnostic Industry*  
September 17, 2015

**The 21st Century Cures Act could be a harmful step backward**

*Washington Post*  
November 19, 2015

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**FDA approves ‘female Viagra’ drug**

*Politico*  
August 18, 2015

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**A new bill in Congress lowers standards for medical devices and drugs, which could harm patients.**

*Washington Post*  
November 24, 2015

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**The Affordable Care Act requires insurance plans to cover the full cost of prescription contraception. That reduces the cost for patients and also reduces unplanned pregnancy and abortion rates,**

*New York Times*

**Our 2015 Health Policy Heroes, Dr. Amy Reed and Dr. Hooman Noorchashm, are pushing for a prohibition of a cancer-spreading device used in many routine surgeries. They explained their concerns to the New York Times.**

**In the Sun Sentinel, Dr. Zuckerman explained that patients will be harmed if Alzheimer’s drugs are approved based on preliminary findings instead of conclusive research. We need new drugs, but we don’t need drugs that don’t work.**

**The “Obesity Industrial Complex” wants to sell you new weight loss products even if they don’t really work.**

*Journal Sentinel*

**After receiving thousands of reports of serious side effects from patients using Essure permanent birth control, federal regulators are reviewing its safety.**

*Associated Press*  
November 24, 2015

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**After a heavy hitting PR campaign, the FDA bowed to pressure and approved the first "Female Viagra," called Addyi. But, its benefits are questionable and it has substantial risks. In Politico, Dr. Zuckerman worries that women will be harmed and that this shows that lobbying can get a dangerous and ineffective medical product on the market.**

*Politico*

**We voiced concerns that President Obama’s nomination for FDA Commissioner has close ties to Pharma in Medpage Today, Medical Device and Diagnostic Industry, and CQ Roll Call, “You have someone who works at a research institute that was funded heavily by industry. When you develop those kind of relationships, you tend to be biased in favor of their point of view.”**

*Medpage Today, Medical Device and Diagnostic Industry, CQ Roll Call*  
November 24, 2015

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**After receiving thousands of reports of serious side effects from patients using Essure permanent birth control, federal regulators are reviewing its safety.**

*Associated Press*  
November 24, 2015
We’ve made amazing strides in learning about the causes of cancer, the risks and benefits of tests to screen for cancer, and new strategies for curing the precise type of cancer that an individual has.

Yet those strides do not improve the lives of many cancer patients and their families. Our Cancer Prevention and Treatment Fund is on the forefront to overcome two barriers to success. The key problem is that many patients are not given all the information they need to help choose the tests and treatments that are best for them.

We’re starting a new study in Baltimore to learn how to better communicate with mammography patients, and we’re working on a national level to share the latest information with all patients.

Our goal: to ensure that all cancer patients get the best possible treatment and to prevent unnecessarily radical and harmful treatments for those with a cancer many experts agree is “not really cancer.”

I got involved in this issue almost two decades ago when I realized cancer treatments can be worse than the disease. I was shocked that some treatments could cause cancer. I also realized that many women were undergoing mastectomies they did not need and that men being screened for prostate cancer were undergoing unnecessary surgery or radiation.

My solution was to start a nonprofit center to bridge the gap between the extensive research being conducted and what patients understand about which treatments will work best for them.

As a new, small charitable research center, we reached out to large cancer charities to work with them, but found that most were so busy organizing events to “raise awareness” about cancer, that they spent little time scrutinizing treatment options to find out what worked and what didn’t, and for whom. In fact, some were providing information to patients that was just plain wrong.

Fortunately, our innovative approach of 15 years ago is gaining widespread acceptance today. Even so, many women and men still receive confusing messages about screening and treatment. Adults without symptoms are strongly urged to get annual prostate or breast cancer screenings that too often frighten them into thinking they have potentially fatal cancer when they don’t.

The result can be the most aggressive treatment, which can unnecessarily harm patients in ways that the cancer might never have.

Our New Research Project is Underway

Our study has just started at the University of Maryland School of Medicine. We are testing new ways of sharing information with patients whose abnormal mammography results have resulted in a diagnosis of ductal carcinoma in situ (DCIS) – a condition that used to be called “very early breast cancer” but is now considered a “marker” for increased risk of developing breast cancer, but is not itself harmful. The goal: provide accurate, understandable information to reduce patients’ fear so that they choose the medical treatment they need, rather than overtreatment that can do more harm than good.

This new study, and the patient booklets we have developed for DCIS patients and for men considering prostate cancer screening, will improve the quality of millions of lives. Research now shows that most men with asymptomatic prostate cancer will live just as long if they put off screening and treatment unless (or until) they develop symptoms. Similarly, we now know that most women with DCIS will never develop breast cancer even without surgery, and most will live longer if they have just the DCIS removed, rather than removing one or both breasts.

For patients with lesions or even very slow-growing types of cancers, “active surveillance” -- no surgery, no radiation, but just regular screening -- may be a very safe alternative to treatment. Many doctors know this. But most patients do not, because most doctors are not very good at communicating that “we’re not exactly sure what will happen so it makes sense to wait and see.”

New ≠ Better

A study published in October reported that many new cancer drugs do not help patients live longer. That includes drugs such as Tafinlar and Cometriq, which each cost more than $100,000 per patient!

That’s why we make sure that patients have all the information they need to make the best decisions for their own personal situation. At the Cancer Prevention and Treatment Fund, we understand that patients’ decisions are based on what they hope and fear and need, not just what they know. Our new study and our booklets for DCIS patients and prostate cancer screening are just a first step to help patients struggling with treatment decisions.
Our Annual Awards Luncheon

On a beautiful spring day in May, 150 women and men gathered at the historic Cosmos Club in Washington, D.C. to honor two outstanding Foremothers for their lifetime achievements and contributions to our community and our country. We also honored two Health Policy Heroes, a couple who has worked tirelessly to keep Americans safe from ineffective medical products.

Autria Godfrey, the event’s Emcee and WJLA TV anchor, introduced the first Foremother of the day, Jodie Bernstein, one of the country’s leading consumer advocates. She has broken many glass ceilings during her career, serving as a role model to millions of women. Under President Carter, she was the first woman appointed General Counsel of the Environmental Protection Agency (EPA), and then the first woman appointed General Counsel of the Department of Health, Education and Welfare (HEW), which became the Department of Health and Human Services. At HEW, Ms. Bernstein drafted regulations giving added muscle to Title IX of the Civil Rights Act, which helped put an end to discrimination against women in colleges and universities.

“If you’ve ever seen a lineup of a lot of guys with ashen faces, that was the coaches.”
- Jodie Bernstein

“One of the responses [to Title IX] that I remember so vividly was, ‘It’ll kill football! It’ll kill football!’” Ms. Bernstein told our rapt audience. Football coaches came to the HEW to protest, she told us, but as she and HEW Secretary Patricia Robert Harris walked into the room, Ms. Harris asked with a straight face, loud enough for everyone to hear, “Now Jodie, is it football or that other game they play in the fall?” Ms. Bernstein told us, “If you’ve ever seen a lineup of a lot of guys with ashen faces, that was the coaches.” She told the coaches that Title IX regulations would be issued and enforced.

Ms. Bernstein was also the first woman to lead the Federal Trade Commission’s Bureau of Consumer Protection, where she investigated marketing of violent movies, music, and video games to children, and cracked down on predatory subprime lenders, scholarship scammers, and advertisers illegally targeting children. Her groundbreaking work to protect online privacy earned her the nickname, “Top Cybercop.”

Looking Back and Moving Forward

In her remarks, Foremother Karen Mulhauser took us back 50 years, during which Ms. Mulhauser has been leading, connecting, and inspiring ever since she joined the March on Washington in 1963. After teaching high school chemistry, physics, and health (the latter is where sex ed was taught), she became Director of the DC office of what is now NARAL ProChoice America, and then Executive Director in 1975.

In her remarks about how things have changed or not changed for women, she talked about her own experience of being raped in her home while her husband was away and her young son was in the next room. A few years later, in 1979, when policymakers were considering whether or not to cut off funding for poor women who became pregnant as a result of rape, Ms. Mulhauser testified that “rape is an act of criminal violence; it’s an expression of men’s anguish against women, a physical power of conscious process of intimidation, as well as ugly sexual invasion. It’s an attack against both body and mind.” She has worked tirelessly advocating for rape victims in the 36 years since.

During the height of the Cold War, Ms. Mulhauser also headed the Center for Education on Nuclear War and established a 60-member coalition called Citizens Against Nuclear War. She started working on presidential campaigns in 1988, culminating in serving as Senior Advisor for Women for Obama in 2008.

It was around her dining room table in 1989 that young women started the Women’s Information Network (WIN), a leadership forum which now has more than 1,000 members to help young women in the DC area take leadership roles in politics and policy. Ms. Mulhauser now serves as chair of the nationwide steering committee of over 150 chapters of the UN Association of the USA. She is leading a nationwide project to enlist community and political leaders to adopt resolutions modeled on the UN Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW).

Health Policy Heroes

Our 2015 Health Policy Heroes are two physicians who have become the most visible and effective patient advocates in the country: Dr. Amy Reed and Dr. Hooman Noorchashm. Both were Harvard Medical School faculty when Amy was treated for what was assumed to be a benign uterine fibroid in 2013. The medical device used in her surgery, a power morcellator, pulverized her fibroid, and with it, spread a hidden cancer. They subsequently learned that Amy’s metastatic uterine cancer was not a “rare complication” of the device, and are working actively to warn patients and doctors, get morcellators off the market, and find a cure for uterine cancer. Read our Spring/Summer 2015 Newsletter (Issue 26) for the full story on our inspiring Health Policy Heroes.
Communities Come Together to Stop Cancer

We held our first Stop Cancer Now Lap-a-thon at Leesburg High School in Virginia, on April 26, 2015. The names of friends and loved ones living with or lost to cancer were posted on the fence surrounding the track, with colored balloons waving in the wind. Students, family members, and other community members lined up to run and walk laps around the track.

Participants registered for one of four teams or as individuals: the Track Team (which included the H.S. track team and friends and family), the Baseball Team (also the H.S. team and friends and family), Team Bob (in memory of Bob Knuff), and Team Ann (in memory of Ann Koch).

Bob Knuff’s wife Michele Knuff, and their children, Abby and Ben, were instrumental in organizing the Lap-a-thon. “It was such an uplifting day, full of very fond memories of loved ones, new stories to hear and people to meet, and helping others in their fight against cancer,” recalls Michele.

The Baseball Team raised the most money, $1,592, for the Lap-a-thon and their members ran 381 laps. Free pizza was provided by Manhattan Pizza as a prize.

The Track Team ran the most laps: 404. As their prize, the Track Team won free ice cream coupons to Hershey’s Shake Shop. Anna Wasko was the top female participant, running 17 laps around the track. Greg Fenner was the top male runner, and he ran 20 laps around the track.

At the end of the Lap-a-thon, all the balloons were gathered into one large bouquet of color. There was peach for uterine cancer, orange for leukemia, pink for breast cancer, purple for leiomyosarcoma, grey for brain cancer, light blue for prostate cancer, and zebra for carcinoid and rare cancers. “We read the names of all the friends and loved ones that we were honoring. It was a powerful moment as we watched in silence as the balloons were released skyward,” recalls Cancer Prevention and Treatment President Dr. Diana Zuckerman.

An enormous thank you to the Knuff family and the wonderful Leesburg High School community. The Lap-a-thon raised over $5,000 to support our Cancer Helpline, which provides free assistance to all who call (202 223-4000) or email (info@stopcancerfund.org).

Special thanks also to our wonderful Gold Level sponsor: Savannah’s of Leesburg, and to our terrific Bronze Level sponsors: the Hershey’s Shake Shop, Potomac River Running Store, ResQ BBQ Catering, Manhattan Pizza, Reston Shirt and Graphic Company, and Mullen Orthodontics.

Another Thank You...

We were honored by the $1,000 donation from the owners of the new Planet Fitness in DC, Victor and Lynne Brick, and the matching donation from Douglas Development Corporation at the ribbon-cutting of the 1,000th Planet Fitness. “Building a beautiful, affordable exercise facility in a low-income neighborhood is a great way to keep people healthy, and help them reduce the risk of getting cancer,” Dr. Zuckerman points out.

Daughter organizes 5K in memory of her mother

Valerie Renee Veney “was a loving, kind woman with a beautiful smile,” according to her daughter, Sherina Garner. When Ms. Veney passed away from lung cancer, Ms. Garner decided to honor her mother’s memory by organizing her own 5K fundraiser. Ms. Garner, along with fourteen supporters, participated in the 5K walk. They donated over $800 to our Cancer Prevention and Treatment Fund. We are so grateful to Ms. Garner for taking action to help children and adults reduce their risks of cancer.

Before she passed away, Ms. Veney advised, “Let people know those cigarettes are killing your lungs slowly. Lung cancer is an awful pain to have.”
Are You Sure Essure is Safe?

Imagine going to your doctor’s office thinking you need surgery, and being told there is a better option: an office procedure that requires no incision or anesthesia and you can go back to work the same day. Who wouldn’t say yes to that?

Thousands of women who already had children and didn’t want to get pregnant again thought so too. They agreed to try a device called Essure, which consists of two tiny coils inserted in a woman’s fallopian tubes to permanently block sperm from fertilizing.

The FDA approved Essure in 2002 as the only non-surgical device approved for permanent birth control. Manufactured by Bayer, the patients are told that, if used correctly, Essure is 99.8% effective at preventing pregnancy for at least 5 years.

Essure: The Falling Star

Soon the shiny new star lost its luster. Thousands of women with Essure started reporting serious complications, including excessive monthly bleeding and excruciating chronic pain. Some women who had been told they were infertile because of Essure became pregnant. Many women had to have hysterectomies in order to remove the device.

Today, more than 24,000 women have reported problems related to Essure on the Essure Problems Facebook group. After meeting with some of these women, we were convinced that there were serious problems with the device and with the studies purporting to prove how safe and effective Essure is. We talked to several women who had been in the company studies of Essure, and that helped us understand the disconnect between the company’s data and the women’s experiences. We learned that numerous women with problems with Essure were basically thrown out of the studies, or their reports of problems were ignored.

Our Center has surveyed more than 1,100 women with Essure problems and we found a consistent pattern of reported complications.

The women harmed by Essure impressed us, and we accompanied them as they met with Congressional staff and FDA officials. They told their stories and backed up their opinions with compelling documentation. As a result of these efforts, the FDA convened a public meeting on September 24, 2015 to discuss the risks of the Essure device.

Kim Hudak is one of the women who has worked closely with us. She participated in one of the company’s clinical trials, and has documents showing that her responses to the study questions were changed so that it would show she was very satisfied with Essure, instead of showing she had terrible complications. (see above)

“WeWith each passing month my symptoms became more severe” - Kim Hudak

At the FDA public meeting, Kim explained that “Within a few weeks I was experiencing a constant sharp pain in my rear hip area, suffering from debilitating fatigue and severe PMS symptoms. By my 3-month follow-up, I was in nearly constant pain.” But she was told the symptoms were not related to Essure, so “I spent years and hundreds of thousands of dollars looking for answers….With each passing month my symptoms became more severe. With each follow-up visit during the clinical trials, I was told the symptoms were unrelated. Within 12 months of placement I had developed pain throughout my body, odd rashes, constant infections, and minor neurological issues. By the time I had a hysterectomy in 2013, I also had cognitive problems, slurred speech, widespread pain and swelling. I couldn’t work and could barely function as a mother.”

She concluded her statement by telling the FDA and their advisors that since Essure was removed 2 years ago, her health has improved dramatically but “This is a small consolation to the almost 15 years that I lost. Please do not let this happen to other women.”
Do E-cigarettes Help People Quit Smoking? Are they Harmful?

We all know that smoking kills thousands of people every year, and that quitting is not easy. Electronic cigarettes, or e-cigarettes, have become very popular because they do not contain tobacco. Instead, they are battery operated to heat a liquid cartridge and deliver flavored nicotine through a smokeless vapor.

You may have heard that e-cigarettes can help people quit smoking, but since there is no evidence that they work to help people quit, it is against the law to advertise them that way. In fact, e-cigarettes could make it harder to quit, since using (“vaping”) e-cigarettes is allowed in many buildings that do not allow cigarette smoking. Without those restrictions during much of the workday, it is harder for smokers to quit.

Although e-cigarettes are marketed as being “safer” than tobacco cigarettes, e-cigarettes use toxic and cancer-causing chemicals. Since e-cigarettes include flavor options such as bubble gum and gummy bears, they are obviously intended to appeal to children as well as adults. Between 2010 and 2014, there were more than 2,400 calls to poison control due to children swallowing the nicotine liquid from e-cigarettes. FDA is still working on the rules to regulate e-cigarettes and require childproof packaging.

Some state and city governments, including Maryland, Kentucky, Wisconsin, New York City, and Philadelphia have banned e-cigarette sales to children under the age of 18. Our Center is actively supporting these efforts to restrict the sale of e-cigarettes, so that our children will not be addicted to nicotine from any type of cigarettes. That is an important way to prevent cancer from cigarette smoking.

Some questions for you:

- Do you want medical products to be safe and effective?
- Do you want FDA and your doctors to listen to scientific research and not just to pharmaceutical company salesmen and PR experts?
- Do you want patients to get accurate, understandable, evidence-based information when they have health questions?

We do too!

Thank you in advance for considering a donation to support our work. It will help us continue to help 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!

Workshop Brings Patient Advocates Together

He has worked tirelessly to speak with and for patients who need support during their journey, through leading support groups and counseling veterans about how to get the services they need. He now has focused his advocacy on improving interactions with the research community. He wants to build on his knowledge of scientific concepts important in measuring clinical trial outcomes. He is also very interested in understanding more about the link between Agent Orange and other chemicals that cause different cancers.

Katherine Leon was 38 years old when she suffered from a heart attack after the birth of her second child. She was otherwise healthy. She remembers how traumatic it was to have a heart attack with no warning, and no one could tell her why. Her doctors passed it off as a rare occurrence and said she would never find enough patients with the same symptoms, so they wouldn’t bother trying to do research. With the help of social media, she went looking for other patients and was able to prove the doctors wrong. She co-founded the SCAD (Spontaneous Coronary Artery Dissection) Alliance and created a patient registry to begin research on the cause of SCAD.

Katherine has volunteered with WomenHeart (an advocacy group for women with heart disease that is one of our coalition partners) and has given many talks about women with heart disease. She strives to increase knowledge about SCAD based on scientific data as well as awareness among physicians and patients. “I fear for the patients who are sent home from the hospital or never even make it there,” she tells us.
Will these women make a difference on a national level?
See story on page 1.

Cancer Prevention and Treatment Fund
We don’t accept funding from drug companies so you can rely on our accurate and unbiased help to prevent and treat cancer.

Donate online at www.stopcancerfund.org
Or CFC #11967
We’re here for you so you can be there for them. Let’s fight cancer together!