

cancer PreventionWorks

Cancer Prevention and Early Detection Information for Your Healthy Life. | preventcancer.org | FALL 2013



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President's Corner



This issue's cover story focuses on making sense of the often shifting currents of health policy. Recent changes in these policies affect us all, yet news coverage of our complex health care system can be difficult to understand. We at the Prevent Cancer Foundation believe that we all need to be familiar with policy changes that touch our lives.

Although health care policies can be confusing and at times inconsistent, Prevent Cancer received monumental news in late July on a research issue we have strongly supported and advocated for since 1999. The U.S. Preventive Services Task Force (USPSTF) issued a draft recommendation for annual low-dose spiral computed tomography (LDCT) screening for lung cancer in generally healthy adults between the ages of 55 and 79 who have at least a 30-pack per year history of smoking and who are either still smoking or who have quit within the last 15 years.

Once this draft becomes a final recommendation and a standard part of clinical practice, lung cancer mortality rates are expected to decrease by at least 20 percent, very likely higher. The Prevent Cancer Foundation has been a supporter of research on high quality, low-dose spiral CT scans since the earliest conversations about the National Lung Cancer Screening Trial (NLST), the largest and most expensive randomized controlled trial in National Cancer Institute (NCI) history. Prevent Cancer has been at the forefront among advocacy groups, in large part due to your generosity.

Here are just a few examples of our support and advocacy for this lifesaving screening tool:

- We collaborated with the UK-based Roy Castle Foundation to host a meeting in 2000 that led to past NCI Director Richard Klausner's decision to start planning the NLST. We also participated in meetings with his successor, Dr. Andrew C. von Eschenbach, who made the decision to fund and launch the NLST.
- We have hosted 10 Lung Cancer Workshops, co-sponsored by the Optical Society of America and the International Association for the Study of Lung Cancer, bringing together oncologists, radiologists, representatives of federal agencies and the pharmaceutical and diagnostic imaging industries, to explore the use of spiral LDCT as a tool for evaluating response to new therapies for lung cancer rapidly and accurately.
- We funded the International Early Lung Cancer Action Project's open source database to provide lung cancer images to any researcher who needed access to high-quality imaging data.
- We worked with Dr. Anna Barker, former NCI deputy director, to support the Reference Image Database to Evaluate Therapy Response (RIDER), to improve lung cancer image processing.

With so many health care reform challenges during the past year, it is encouraging to take a moment to acknowledge the excellent work being done in the field of cancer prevention and celebrate victories like the draft recommendations for low-dose CT lung cancer screening.

The Foundation takes pride in its support of many policy initiatives that utilize the most recent scientific evidence to promote cancer prevention and early detection. This issue of *cancerPreventionWorks* sheds light on the current landscape of cancer prevention and health policy. Knowledge is power. The more we know, the more able we are to not only *Stop Cancer Before It Starts!* but perhaps someday, eliminate it entirely.



Prevent Cancer 5K Walk/Run knocks it out of the park for cancer prevention!

On Sunday, September 29, Prevent Cancer Foundation welcomed hundreds of enthusiastic participants to the fifth annual Prevent Cancer 5k Walk/Run. Corporate sponsors, partner organizations, local companies and families came together to support Prevent Cancer's mission of saving lives through cancer prevention and early detection. This year's event boasted a scenic 5k route around the beautiful Capital Riverfront area with a start and finish inside Washington Nationals Park. After completing the 5k course, participants practiced their swing inside the Nationals batting cages, received free cancer screenings provided by local health partners, toured the Prevent Cancer Super Colon™, played games and enjoyed free food and other giveaways.

Prevent Cancer Foundation is grateful to individuals and businesses in the community for joining with us to promote healthier and more active lifestyles and for donating funds to advance cancer prevention research and educate communities nationwide about prevention and early detection.

We look forward to building on the success of this great community event. Be on the lookout for the announcement of the 2014 date and make plans to join us at next year's Prevent Cancer 5k Walk/Run!

To view more photos from the 2013 event, visit www.preventcancer5k.org.

Dr. Ann's hot & healthy superstar chili

Serves 35-40 people - Great for a party!

1/2 cup of extra virgin olive oil
1 3/4 lbs. chopped yellow onion
3 red bell peppers, chopped
2 lbs venison sausage, casing removed
(can substitute Andouille)
8 lbs ground venison
(can substitute extra lean ground beef)
2 tbs of freshly ground pepper
2 12-oz cans of tomato paste
3 tbs of fresh, minced garlic
1/2 tsp of cayenne pepper
3 1/2 oz of plain chili powder
3 oz of ground cumin
4 tbs of Kosher salt
4 1/2 tbs of dried oregano
3/4 cup of Dijon mustard
4 1/2 tbs of dried basil
5 large cans of Italian plum tomatoes - drained
3/4 cup of red wine
1/4 cup of lemon juice
1/2 cup of fresh dill
1/2 cup of chopped fresh parsley
4 cans (15 1/2 oz. each) of black beans
3 cans (5 1/2 oz. each) of pitted and chopped black olives

Heat olive oil in a large stock pot. Add onions and peppers and cook over low heat until tender. Add sausage and ground meat and heat over medium heat until browned. Drain fat. Reduce heat to low and stir in black pepper, tomato paste, garlic, cayenne pepper, cumin, chipotle powder, Dijon mustard, salt, basil, and oregano. Add tomatoes, red wine, lemon juice, parsley, dill, and black beans. Simmer uncovered for 20 minutes. Add olives, correct seasoning, and simmer for another 5 minutes. Garnish with plain yogurt and chopped spring onions (optional).

Prevent Cancer Super Colon™ visits the Latin American Festival in Worcester, Mass.



The Prevent Cancer Super Colon™ traveled to Worcester on August 17 for the 23rd annual Latin American Festival. The exhibit was hosted by UMass Memorial Health Center. Volunteers distributed magnets, bracelets and the Prevent Cancer "Guide to Preventable Cancers" in English and Spanish. Among the nearly 500 visitors were Congressman Jim McGovern and Congressional Families Cancer Prevention Program Executive Director Lisa McGovern. Foundation staff were able to educate visitors about the importance of colorectal screening, and representatives from UMass were available to schedule colonoscopies, although we were pleased to learn that many visitors had already been screened for colorectal cancer.

The Latin American Festival featured live music, dancers and authentic Latin food. Prevent Cancer Foundation staff had a great time experiencing Latin culture and raising awareness of colorectal cancer prevention. Cancer is the leading cause of death for Hispanics in the U.S., and colorectal cancer is the second most commonly diagnosed cancer in the Hispanic community. Adults aged 50 and older are at risk for colorectal cancer, especially those who smoke, drink excessively, eat a lot of red meat and aren't physically active.

Learn more about the Prevent Cancer Super Colon™ at www.preventcancer.org.

Best practices in grassroots advocacy workshop

In July the Prevent Cancer Foundation hosted a unique workshop to help other organizations in the national health-related advocacy community learn how to build effective, engaged grassroots advocacy networks. The workshop provided a forum for discussion with experts about the strategies and tactics involved in helping advocates harness their passion for a cause and have that passion make better quality health care more accessible to more people.

Grassroots advocates are the key. They are the essential ingredient – the lifeblood of a national advocacy organization like the Prevent Cancer Foundation. Our advocates help save lives by carrying the Foundation's crucial messages, by translating them into reality. They take steps in their own lives to prevent cancer or to detect it as early as possible. They share those lessons with their families, friends and others in their local community. They also share them with their state and federal legislators. By participating in some



or all of these activities, our advocates amplify our voice a thousand-fold and give our messages strength and meaning.

The workshop speakers represented a variety of organizations and viewpoints, but all shared some basic advice. They advised attendees that grassroots organizing is ultimately a human enterprise best encouraged by harnessing the power of advocates' personal experiences to effect social change. The speakers cautioned it wasn't easy, and took time, patience and careful planning. They suggested that an organization's advocacy program be focused on clear-cut goals, but adaptable as the national political and scientific landscapes changed.

These experts also noted that new Internet-based tools are excellent adjuncts in organizing a grassroots network, but never a substitute for the coordination, collaboration,

and communication needed among staff, advocates and policymakers to ensure an effective program.

In a survey immediately following the meeting, 93 percent of the attendees said the workshop was worthwhile and 95 percent expected to take back information to their organizations. The bottom line... we all left the workshop with a better understanding that, as one of the speakers noted, "Advocates are a force multiplier in the fight against cancer." They are essential if an organization is to fulfill its mission. Therefore, above all, organizations should recognize, as does the Prevent Cancer Foundation, that advocates give their most valuable resource – their time – and in doing so, they make a difference.





Navigatin currents o policy

I remember a high school exam question... "What is a famous quote from the English classic, 'A Tale of Two Cities?'" The answer was "It was the best of times, it was the worst of times, it was the age of wisdom, it was the age of foolishness...." That quote certainly describes the healthcare policy scene today.

There have been praiseworthy policy accomplishments that benefit everyone who has been touched by cancer or who knows someone who has been. There are hopeful policy initiatives on the horizon. Policy makers can translate them into a reality that will benefit millions of current cancer patients and survivors and all of us who wish to prevent cancer or detect it early when it is most treatable. These are policy "calm waters." But there are troubled, turbulent waters as well.

The Affordable Care Act (ACA) is an excellent example of both sides of the policy coin. In many ways, an outstanding gift to cancer patients, the ACA precludes insurers from denying coverage for pre-existing conditions and there will no longer be any annual or lifetime limits on coverage for essential health benefits. People who purchased

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coverage after 2010 or will purchase it from now on also will have access to preventive services with no deductibles or co-pays. Calm waters.

However, it appears implementation of the ACA is running into technical and political troubled waters. Millions of consumers who must start obtaining coverage on October 1 are confused by or totally unaware of the process and there continues to be significant political turmoil about the law in general.

Further into policy turbulent waters, in June, the Senate Finance Committee released a report discussing options for potential reforms to tax laws for tax-exempt organizations and charitable giving. Many could negatively affect advocacy organizations and thus seriously impede the way the Foundation works to save lives through cancer prevention and early detection. Congress has not yet taken action on the reform options, but we will be keeping a close eye on this issue throughout the coming year.

The results of sequestration – the automatic spending cuts in the federal budget that went into effect in March – had significant negative effects in the health care sphere, particularly for the Centers for Disease Control and Prevention and the National Cancer Institute. Cuts in these agencies' budgets are leaving people with less access to life-saving cancer screenings. These cuts are also depriving researchers of precious dollars for studies to find new diagnostic and therapeutic tools. Still more troubled waters.

But, back into calm waters. With the Prevent Cancer Foundation as a leading voice, Congressional champions and patient advocates brought considerable pressure on the Food and Drug Administration (FDA) to issue new

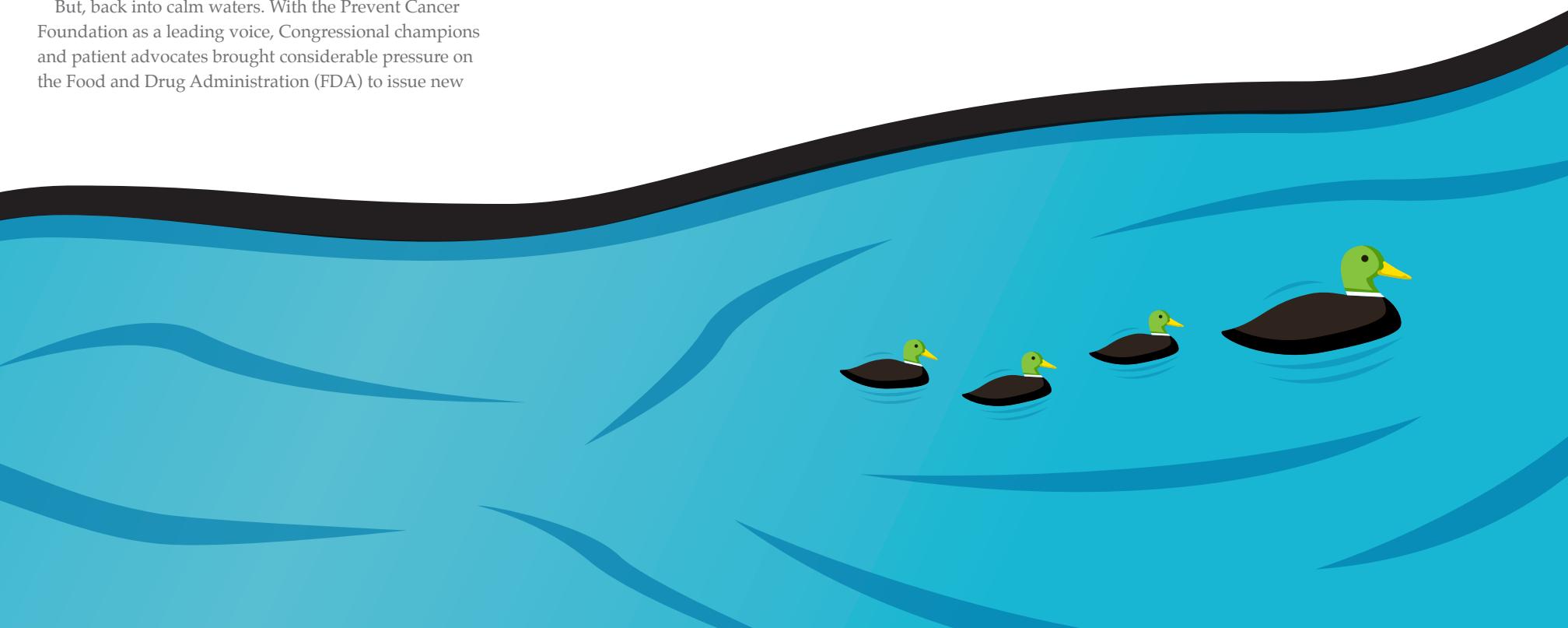
regulations about tanning beds. These regulations would require labels on the beds warning young people not to use them and to undergo skin cancer screening. The suppliers of tanning beds would have to prove to the FDA that they are safe (e.g., the electrical systems are safe, the lamps emit the correct amount of energy, timers work correctly). The FDA responded by asking for public comment, a good sign that they will move to issue these new regulations.

Finally, still waters allow successful navigation for those busy saving lives by working to prevent cancer or detect it early. The Prevent Cancer Foundation was heavily

involved in successful advocacy efforts focused on lung cancer screening. In late July, the U.S. Preventive Services Task Force issued a draft recommendation to screen people who are at high risk for lung cancer with high-quality, annual, low-dose CT scans. Implementing this screening according to guidelines can prevent a substantial number of lung cancer-related deaths. Lung cancer screening now joins three other screening procedures, breast, colorectal and cervical, which the Foundation has worked diligently to promote over the years. Of note is that lung cancer takes more lives than the other three combined.

How can an advocate – you or me – navigate both the calm and turbulent waters among the policy challenges presented by this country's complex and expensive health care system? We get frequent questions and comments from our much-appreciated donors, advocates and others who follow the Foundation's activities: "What can I do?" "I'm only one person, one voice." Each voice amplifies another. As you can see by the Foundation's policy accomplishments, our combined voices make a difference. Please send me a quick email – Karen.kaplan@preventcancer.org – saying "Add my voice", and I'll write telling you about all the ways you can do that. Happy navigating!

‘What can I do? I’m only one person, one voice. Each voice amplifies another. Our combined voices make a difference.’



On the road again with **AMGEN** and the Amgen Tour of California



Prevent Cancer Foundation is honored to be one of four nonprofit organizations partnering with Amgen on Breakaway from Cancer, an educational initiative of the Amgen Tour of California cycling race.

Breakaway from Cancer nonprofit partners empower patients with education, resources and hope across the continuum of cancer. We represent a diverse team with expertise in preventing cancer, facing a new diagnosis, caring for a loved one and struggling with financial issues. Prevent Cancer helped staff the Breakaway tent throughout the Amgen Tour of California, which began May 12 in Escondido and ended May 19 in Santa Rosa.

Paige Schechtman:

"I would rather be pale than have cancer"

My motto in life is that I would rather be pale than have cancer. Unfortunately, that was not my motto until I was 43 years old. A tan is a good thing, right?

I always thought that I looked better tanned, that everyone looked better tanned. I spent many days in the hot sun burning my skin, followed by peeling days later and then a bit of a tan. I did the tanning salons, too. I never thought about skin cancer. If someone mentioned it, I thought they were "old", and I didn't need to listen to them. I was fine because I was tanned and looked good.

When I was 39 years old, I had thyroid cancer. I wasn't scared because that is how I deal with things. I had to be strong. I am a single mom and my then two and 1/2 year-old needed me. I had surgery and, radiation and was fine. I get my blood checked once a year now and take Synthroid daily.

Fast forward to 43 years old: I am with a friend, and she asks me about a mole on my arm. I tell her that I have had it checked several times, and it is fine. I have always had freckles everywhere.

I have a few moles but lots of freckles. My son started asking me about the mole on my arm. I told him what it was, and he told me it was ugly. I listened and went to the doctor. I asked him if he could remove it with a biopsy so that my insurance would cover it. I was being vain, and I admit it.

When my doctor called a few days later to tell me the biopsy came back, and it was a basal cell carcinoma, I was shocked. For some reason, it hit me harder than being told I had thyroid cancer. He explained that I would have



Mohs surgery to remove it. It is a precise method to treat skin cancer, limiting damage to healthy tissues. I was ready for the surgery and oddly, it wasn't bad. Even with great insurance, it is expensive. The scar is there but doesn't look so bad.

Suddenly, wanting to be tanned seemed silly. I remember stopping on the way home from the surgery to get medicine and coming back to my car only to find a business card for a tanning salon on my windshield. There were four tanned, beautiful women in bikinis on the card. I looked down at my arm and saw the large bandage, wrapped like a mummy. I tossed the card in the trash. It was hard not going to the tanning salon and showing them my arm to warn customers.

I am now 45 years old and have had a total of five Mohs surgeries. Five were basal cell carcinomas. Yes, you read that right: five. The next one was in my eyebrow. This one was tricky as it had to be done by a plastic surgeon. It was scary, painful and expensive. I lost a few hairs in my eyebrow that will never come back, but the cancer is gone. Next one was on my lower back. This one really hurt! The last two were

about an inch apart from each other on my upper arm.

I have had five basal cell carcinomas in less than 18 months. I have had the doctor burn off over twenty precancerous spots. I have body checks four times a year. I use sunscreen all of the time and still stay out of the sun. I have gone on vacation and made sure that I was under several umbrellas without a single speck of sun touching my body. I am pale and proud of it.

I know that 45 sounds old if you are in your teens or twenties. But from my perspective, please take my warning. No matter how much you think the tan looks great, the body checks, surgeries, bills and phone calls telling you that yet another biopsy has come back as cancer, are not worth any tan.

I urge you to use sunscreen every day and get a full body check twice a year. Don't lie in the sun, don't go to any tanning salon. If you really need a tan, get a spray tan. Better yet, believe the same thing that I believe: pale is better than cancer.

Prevent Cancer visits Nebraska's Cattlemen's Ball

In June, the Prevent Cancer Foundation offered cancer screenings and education at the Cattlemen's Ball with our clinic partner of 16 years, the Fred and Pamela Buffett Cancer Center, one of the crown jewels of the University of Nebraska Medical Center. The Ball is one of four annual activities of the Nebraska State Fair Project. Prevent Cancer offered attendees home-based colorectal cancer screening kits, dermascans that show sun damage on the skin and face and free sunscreen packets. We also interacted with attendees by asking them "quiz" questions about colon cancer and how to lower their risk or detect colon cancer early when it is most treatable.





Prevent Cancer webcasts educate and inform viewers

To continue to find new ways to share cancer prevention and early detection information, the Prevent Cancer Foundation, in partnership with the National Association of Broadcasters and the Foundation's Congressional Families Cancer Prevention Program, hosted two live webcasts, "Family Medical History: Why and What You Should Know" on May 1 and "Healthy Strategies for Children and Families" on June 21.

The "Family Medical History: Why and What You Should Know" panel was moderated by Dave Dubin, a three-time cancer survivor and advocate for cancer screening and genetic testing. Panel members were a diverse group of leading experts and advocates on the topic:

Anna Maria Izquierdo, M.D., Primary Care Physician and Executive Director of Care for Your Health

Beth N. Peshkin, MS, GCG, Associate Professor of Oncology and Senior Genetic Counselor at Georgetown Lombardi Comprehensive Cancer Center

Allyn Rose, Miss District of Columbia, a family medical history and cancer prevention advocate.

The panel discussed a range of subjects relating to the importance of knowing one's medical history including:

- How knowledge of your family medical history can help reduce your risk of cancer and other chronic diseases.
- Strategies for learning about your medical history from family members
- Genetic testing and genetic counseling.

"Healthy Strategies for Children and Families" offered ideas for parents and caregivers on leading their families down a path to good health, despite the roadblocks they may face along the way. The panel included parents, family advocates and health experts. Moderated by Jennifer Kolodziej, noted Mommy Blogger and author of the "Tastefully Childish" blog, the panel included:

- Debra Cincioni, President and Co-Founder of Moms of America, a membership-based organization for moms and others who nurture family, friends and youth.
- Derek Huffman, PhD, Co-Director, Healthy Aging Physiology Core at the Albert Einstein College of Medicine, obesity researcher and past Prevent Cancer Foundation fellow.
- Dhanya Puram Limaye, M.D., F.A.A.P., Pediatrician at Arlington Pediatric Center.
- Ginny Wright, Founder of BbG Fitness, exercise and nutrition expert Subjects relating to the webcast topic included family nutrition, exercise, sun safety and childhood obesity.

Online viewers submitted questions, via Facebook and Twitter, throughout the live webcasts for the panelists to answer. Enthusiastic audience participation added to the lively and informative discussions. Special thanks to the National Association of Broadcasters for hosting the webcasts and providing the technology and talents of NAB's staff and to our generous sponsors Amgen, GlaxoSmithKline, Bayer, Pfizer and Bristol Myers Squibb.

Recordings of both webcasts are available to view by visiting preventcancerwebcast.org.

Prevent Cancer funds community organizations focused on education, awareness and screening. Thanks to donations from generous donors like you, the Prevent Cancer Foundation awarded four \$10,000 community grants to projects focused on cancer prevention education, awareness and screening. The Foundation received 107 grant applications from organizations in 31 states, demonstrating the value and strong need for this program.

"This funding will make a notable difference in our ability to get the word out to teachers about our youth education program, Sun Smart U."

Whitney Potter,
Director of Special Projects at
the Skin Cancer Foundation

North Dakota – Custer Health seeks to address low screening rates among American Indians on the Standing Rock Reservation by working with the community to conduct worksite "lunch-and-learn" cancer education sessions with 150 men and women and to provide screenings.

Kentucky – Lake Cumberland District Health Department is partnering with school-based health clinics to provide vaccines and raise awareness of the human papilloma virus (HPV) and its link to cervical cancer. This project aims to increase the HPV vaccination rate among middle and high school students in south central Kentucky.

Maryland – Nueva Vida is providing effective and culturally relevant breast and cervical cancer education to 250 underserved Latinas and working to improve health outcomes through patient navigation and access to quality cancer screenings in the Baltimore metropolitan area.

Nationwide – The New York-based Skin Cancer Foundation is increasing knowledge about skin cancer prevention and early detection through Sun Smart U, a youth education program for middle and high school students. The grant supports promotion of the engaging, interactive program to educators nationwide.



Stop Cancer Before It Starts!

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THE LAST WORD

Tax reform and charitable giving

Tax reform! When the U.S. House of Representatives and the Senate go back into session

in September, reforming the tax code once again will be on the legislators' agenda. The Chairmen of the Senate Finance Committee and the House Ways and Means Committee have agreed to undertake a comprehensive reform of the tax code, its first major update since 1986. Since then, the economy has nearly doubled in size, businesses are becoming increasingly international and the Internet has changed the way all of us do business. The tax code no longer fits the way we do business.

Nor does the current tax code necessarily fit the way we do philanthropy. In a slowly recovering economy, donors need encouragement to dig deeply into their pockets to help fund programs about which they are passionate. An example is the Prevent Cancer Foundation's programs to save lives by preventing cancer or detecting it at the earliest possible moment. However, some of the tax reform options on the table, instead of providing incentives for donors, may do just the opposite.

The Senate Finance Committee released a compilation of reform options addressing rules and laws applicable



to tax-exempt organizations and charitable giving. These options were suggested by bipartisan commissions, tax policy experts, members of Congress and witnesses at committee hearings. Although the report presents these possibilities, it does not present a particular plan or approach favored by the committee.

The report also notes the importance of maximizing the efficiency and effectiveness of charitable giving incentives. However, of serious concern to worthy charities like Prevent Cancer, key among the options is eliminating the deduction for charitable contributions or fundamentally reforming the rules.

Like most non-profit organizations today, the Foundation relies heavily on the generosity of donors like you.

Each year, as a result of your support and commitment to our mission, individuals in communities across the country benefit from our funding of cutting-edge research, education and community outreach programs, free cancer screenings and educational exhibits. Programs such as ¡Celebremos la vida! (Let's celebrate life!) continue to receive praise and appreciation each year from Latinas who receive free mammograms and Pap tests to detect breast and cervical cancer.

Our health and wellness programs have expanded to provide free oral health screenings, sunscreen packets and home-based colorectal cancer screening kits for thousands of state fair attendees in Midwestern states. And, with your support, our annual professional development conferences continue to grow as increasing numbers of public health professionals, physicians, nurse practitioners, cancer researchers and patient advocates attend them, adding to the national body of knowledge about cancer prevention and early detection, that is so vital to saving lives.

We understand you have a choice about which charities you support, and we are grateful that you have chosen to include the Prevent Cancer Foundation among them. By renewing your commitment to Prevent Cancer, you will help ensure that countless individuals won't have to hear those devastating words, "I'm sorry, it's cancer." If you have a question about how your charitable giving will help benefit the Prevent Cancer Foundation, please contact Tanya Blue, Director of Major Gifts and Planned Giving at 703-837-3684 or Tanya.Blue@preventcancer.org