



e-newsletter

December 2009



The Oral Cancer Foundation
awarded "best in the US" - Small Non-profit category



CANCER FIGHTERS
WINNER 2009

GREAT Nonprofits

'Tis the Season to Give

We would like you to think for a moment about non-profit foundations in general. Why do foundations like ours exist? There are many reasons, but primarily they come into being because a particular need is not being met adequately through any other means. They exist to increase awareness of that need or problem, drawing public, professional, and governmental attention to its unique situation. Foundations then apply that public awareness to effect change. Worthy endeavors in the form of non-profit foundations abound. Those that seek to protect our environment, that help shed light and elucidate diseases and chronic conditions that burden lives, others that champion social causes, or lift the human spirit. All worthy in their own right. Our government cannot allocate the resources to every worthy cause which exists. Professional associations in the arts, sciences, medicine, education, etc. also cannot meet the demands of every need, even within the more finely tuned scope of their efforts. Foundations attempt to fill these voids, and their efforts and contributions have

Meet the Key Staff at the Oral Cancer Foundation:

Brian Hill- Founder & Executive Director

Chester Deitz- Director of Internet Technologies

Megan Cannon- Director of Administration/ Social Media Coordinator

Sheldon Sax- Manager, OCF News Site

Susan Lauria- Events & Volunteers Coordinator

Candy Sparks- Director of Strategic Relationships & Development

been profound. They have protected endangered species, preserved habitats and wilderness, championed the rebirth of inner cities and provided opportunities for the underserved and the less privileged of the world's populations. They have fed the hungry and moved governments to change. Cures for disease and important medical research are furthered by their involvement, and they have enriched lives with exposure to the arts.

Of course many more positives could be added to this list, but their most important contribution is more subtle; they give voice to those who alone may not be heard. When an idea or cause is acted on by a chorus of voices speaking in unison, it will be heard. The individual voice, amplified through a foundation becomes the catalyst for change and empowerment, the creator of hope, and the general improvement of the quality of our existence.

People become involved in foundations for a simple reason. They share a common value with the goals and visions of the foundation. Through their association, they add their voice, their time, and their money to a cause which speaks to their own individual value system. In a world where the focus frequently seems to be on the selfish enrichment of individuals and personal consumerism, those who join with a cause set themselves apart. When you hear of a foundation's success in a particular endeavor, it is in reality, the thousands of private individual voices of their members whose synergistic contributions have effected that change.

While foundations and their causes often are able to accomplish a particular goal through the benevolence of a major corporate partner, or private individual with the financial independence to altruistically further that effort, most financial support arrives in thousands of small increments. The individual memberships and small donations of concerned and more importantly, involved, private individuals allow a foundation to carry out both its mission and vision. Please be a part of that chorus for change by adding your voice and financial assistance to help OCF. **While other cancers are seeing a decline in their incidence and death rates, in 2007 alone oral cancer rates rose by 11%. [We need your help... today.](#)**

Twitter Hype

There's a lot of hype spreading on Twitter lately about Mouthwash and Oral Cancer? Is Alcohol-based mouthwash really a risk factor for oral cancer? Here's an article to set the record straight:

Mouthwash Cancer Link Questioned

Mouthwashes that contain alcohol should only be available on prescription from a dentist because of a possible link with oral cancer, according to researchers in Australia.

David Hastings- Senior Patient Advocate

Laureen Brady, RDH- Liaison to the Dental Hygiene Community

[Click here to see the full OCF Key Staff page](#)

OCF 2010 Event Calendar

March 6th- USC Oral Cancer Walk, Los Angeles CA

March 13th- Oral Cancer Walk, Nashville TN

April TBD- NYU Oral Cancer Walk, New York NY

April TBD- Walk and Rock, Hermitage PA

April TBD- University of Pennsylvania Oral Cancer Walk, Philadelphia PA

May 22nd- Oral Cancer Walk, Pittsburgh PA

June TBD- Oral Cancer Walk, Chicago IL

June 20th- Oral Cancer Fundraiser with the Traveling Baseball Babes, Catiague Park NY

September 25th- David Nasto Memorial Walk, Andover NJ

September 25th- David Nasto Memorial Walk, San Diego CA

September 25th- Oral Cancer Walk, Torrance CA

October TBD- Walk the Rock, Boston MA

We can ALWAYS use

Professor Michael McCullough and Dr Camile Farah looked at previous research to see whether using mouthwashes containing alcohol is linked to oral (mouth) cancer. The review highlights the fact that certain mouthwashes contain more alcohol than some alcoholic drinks.

Drinking alcohol is one of the main risk factors for oral cancer, along with smoking. Smoking and drinking together increase the risk even further. The researchers recommend that mouthwashes that contain alcohol should only be available on prescription from a dentist, and should only be used for short periods of time to treat specific conditions.

However, Dr Nigel Carter, Chief Executive of the British Dental Health Foundation, told the health information team: "The public can continue to use alcohol-containing mouthwashes with the utmost confidence. There is absolutely no proven link with mouth cancer. This is a poor piece of research and has led to unnecessary scaremongering."

One of the studies that the researchers looked at showed that mouthwash users were more likely to develop oral cancer, even if they didn't smoke or drink.

However, this study was carried out in Latin America where mouthwash isn't routinely used. Those who used it may have been trying to treat problems caused by poor oral hygiene. It may have been this poor hygiene, rather than the mouthwash use, that increased the risk of oral cancer. To further cloud the issue, the study authors didn't ask the participants if the mouthwash they used contained alcohol.

Yinka Ebo, Cancer Research UK's Health Information Officer, explained: "It's important to note that mouthwash users may be more likely to have poor oral hygiene, so more research is needed to find out whether it's the mouthwash or the poor oral hygiene that increases the risk of mouth cancer."

Both the British Dental Health Foundation and Cancer Research UK say more research is needed before any link between mouthwash and oral cancer can be confirmed.

Oral Cancer Survivor Stories

Shaylynn Grant-



One month and one day after I was married, I found myself sitting in the waiting room at one of the local hospitals waiting for my name to be called into a biopsy surgery on my tongue.

your help! If you would like to volunteer at any of these events, or have your own please contact OCF's event coordinator: Susan Lauria

susanspeaks@aol.com

Winterize your diet



Think you're eating healthy? Canadian scientists recently compared the cancer-protective properties of 33 vegetables and found that the most powerful tumor fighters- brussels sprouts, leeks, beets, and kale- are often among the ones least likely to land on your plate. If you find these winter vegetables hard to swallow, use our tips to unlock their flavor potential.

1. Brussels sprouts- remove the outer layer of leaves, trim the stems, and toss with olive oil and sea salt. Place them on a baking sheet and roast at 425 degrees F until they're nicely browned.
2. Leeks- Many restaurants offer potato- leek soup in the winter, but you can also finely slice leeks and add them to omelets, salads, and rice.
3. Beets- Wrap one or two beets in foil and bake them



Two days before Thanksgiving I was diagnosed with Squamous Cell

Carcinoma on the left side of my tongue. My husband and I were baffled at how I could be diagnosed with cancer at the tender age of 23. The holiday season of 2008 flew by, filled with doctors appointments. After getting several opinions I decided to do a radical neck dissection & a partial glossectomy. I was released from the hospital with good news on Christmas day. I was told that there were clear margins around the tumor they removed from my tongue and out of 37 lymph nodes that were removed from my neck there was only one lymph node that was positive, and it was only one millimeter of cancer and it was still encapsulated. So it looked as though my husband and I would have a great start to 2009! I decided to go back to school and get my degree in Radiography and we were working on getting our living situation and finances back in order since my husband had been layed off. I had a Pet scan done in June where two separate areas the doctors were concerned with. In August I had a bilateral neck dissection where the doctors found that the cancer had wrapped itself around my perotid gland and had spread to a lymph node in the opposite side of my neck. After a short recovery in the hospital I started gearing up to begin Chemo and Radiation. It was quite possibly one of the hardest things I have ever been through & thankfully I have had a wonderful support system to help me through it all. I finished eight rounds of Chemo and 37 radiation treatments on November 19, 2009, exactly a year since I had been sitting in that hospital waiting room waiting for a biopsy. Read more of my story on my blog site:

www.remissionorbust.blogspot.com

Jeanna Richelson-



I was diagnosed with Squamous Cell Carcinoma with unknown primary in June of 2001. I had a swollen lymph node on the right side of my neck and when a round of antibiotics made no change, I was ordered a needle biopsy that confirmed I had cancer. I was only 36 years old and a non-smoker so it was rare for me to have this type of cancer. Since it

was in the lymph node, it was secondary which meant it was coming from another source, the primary, and now we have to find it. I was sent to have all kinds of tests to see where the cancer is so we can begin a treatment plan. All tests came back negative,

in a 350 degree F oven for an hour or until they're cooked through. Then cut them into cubes to toss into a salad of greens and crumbled goat cheese. Add a drizzle of walnut oil.

4. Kale- To temper kale's bitter taste, gently saute it with olive oil, balsamic vinegar, chopped garlic, and pine nuts.

5 Ounces of Prevention



Fortify your immune system with fungi: Mushrooms may help stave off sickness and disease, reports a new Tufts University study. When the researchers supplemented the diets of mice with white button mushrooms, they found the rodents had enhanced activity of "natural killer cells," compounds that fight viruses and cancer.

Five ounces of the 'shrooms daily may provide you with a similar effect, say the study authors, although more studies are needed to confirm this.

Illinois Chapter

this is good and not so good, we didnt find where the cancer is coming from.

I had surgery, a radical neck dissection and tonsillectomy. The cancerous lymph node was removed as well as many others in the right side of my neck to check for cancer. The tonsils were also negative of any cancer. I began 30 radiation treatments to the right side of my neck, I was very tired and burnt but not many other side effects, I did pretty well. I was watched by the surgeon and radiologist every month for one year and then it was every other month. 18 months later I had another swollen lymph node, this time under my chin. I immediately had a needle biopsy and CT scan which came back positive, the primary source of cancer is still present. By the look on Dr. Greers face, I knew we were in trouble. Robert asked him if he should take me to Houston, Tx to MD Anderson which is the number one cancer clinic in the country, he welcomed the help.

After many tests, the primary cancer was found in the base of my tongue, it was so small that none of the tests were finding it. After a consultation visit in Houston and many tests and doctor appointments, I would have to have surgery to remove half of the base of my tongue. Robert and I had only been married for six months , I was happy and felt great, I couldnt believe this was happening. What a true test to a marriage, new or old.

Dr. Greer did another radical neck dissection to remove the positive lymph node and many other lymph nodes, this time on the left side of my neck. After a couple of weeks to heal, we flew to Houston for the big surgery. On Feb 21st, I had the surgery to remove almost half of my base of tongue, this is the part down in your throat that pushes food down when you swallow. The plastic surgeon took tissue and an artery from my forearm to replace the empty space in my throat. The surgery was about nine hours. I had a trachea which was removed after a month and I had a feed tube in my tummy that wasn't removed until about 9 months later.

I had my first treatment on Aug. 1st, one treatment every 3 weeks until I had 5 treatments. We had it done on Fridays, I felt fine Saturday but it would hit me Sunday and would last a week. I was nauseated, weak and just sick. My bones hurt and it felt like there was a war going on inside of my body, it was a weird experience. I lost my hair, and so did Robert! As soon as mine began to fall out, we shaved it and he shaved his too, we were twins. It had its advantages! Hair is over rated! It takes too much time to style and you spend a fortune on hair products.

I went to Siskin Hospital for 3 months for swallow therapy. A new treatment, VitalStim Therapy is used in both patients with mild dysphasia and in those who are feeding tube dependent. VitalStim Therapy re-educates the muscles involved in swallowing by using

Launch Event



On Friday, October 30th, the Illinois Chapter of the Oral Cancer Foundation held its launch party at the Stone Lotus Lounge in Chicago. It was a great event! The evening included a open vodka bar, silent auction, raffles and speakers. It also included some great music by local musicians. About 130 people attended the event to learn more about oral cancer, the OCF and how they can help in spreading awareness and early detection. It was also a time to promote the first oral cancer walk to be held in Chicago next June. All in all, it was a very successful night!

A Greener Hospital Stay



electrical stimulation in a series of painless, hour-long sessions. This would send messages to my brain to say "this is how I swallow now". In November 2003, the feed tube came out, this was a great day!

At the end of 2005, I had another recurrence, this time to my thyroid. We flew back to Houston for surgery and over 30 more radiation treatments. I've had over 90 radiation treatments, several surgeries and chemo treatments. I am a survivor. I have daily challenges, like eating but I am still working and trying to live a somewhat normal life. I don't have a feed tube but everything goes in my vitamix so I'm living on cream soups and smoothies! [Read her full story](#)

Are You an Oral Cancer Survivor with Frequent Dry-mouth?

Every year ~35,000 people in the United States are diagnosed with mouth and throat cancer. Most are treated with radiation and surgery. One side effect of radiation is damage to cells in the salivary glands. This damage reduces the amount of saliva in the mouth, which can cause problems such as dry mouth (xerostomia), difficulty swallowing, tooth decay, and yeast infections (thrush).

There is no cure for salivary gland damage caused by radiation. Dry mouth caused by radiation is often treated with artificial saliva or medicines that increase saliva flow. However, most treatments for dry mouth only treat the symptoms and bring temporary relief. They do not reverse the damage to the salivary glands.

Researchers at the National Institute of Dental and Craniofacial Research are investigating a new treatment for dry mouth. This treatment involves the insertion of an Aquaporin gene into the remaining cells of the salivary gland. This gene makes a protein that carries water across cells. To get the gene into the salivary cells, the gene is combined with a common cold virus. The Adenovirus is modified so that it will not cause infection in the body. The virus and gene are injected into one of the salivary glands. Research in animals has shown that this treatment can increase saliva flow for a short period of time with very few side effects.

The overall purpose of this research study is to learn more about the safety of this treatment in humans. A second purpose is to determine if the treatment can increase salivary flow and improve dry mouth. We expect that any improvements in dry mouth will only last a few days to two weeks. If this treatment increases salivary flow, it may be possible to develop a longer lasting treatment.



The next time you visit someone in the hospital, skip the flowers and bring a potted plant instead. Researchers at Kansas State University found that when people recovering from appendectomies had plants in their hospital rooms, they needed up to 36 percent less pain medication than those whose rooms were foliage-free. "Being in an environment with living plants reduces stress, which in turn lowers pain perception," says study author Richard Mattson, Pd.D. While the type or quantity of greenery didn't matter in the study, stick with something hardy, such as a fern or clover plant.

We Give to Get



We Give To Get has partnered with ActofGood.org and a variety of Chicagoland businesses to give you a great offer while giving back to OCF. They offer limited time (usually

The study takes one year to complete and requires ten inpatient visits to the National Institutes of Health Clinical Center in Bethesda, MD. These visits typically last 1 to 4 days. The first two visits will help the study team decide whether you are eligible. The investigational treatment is given one time on the third visit. The other seven visits will help the study team learn more about the treatment.

You may be eligible to participate in this study (NIH Protocol 06-D-0206). There is no cost for participation or any tests associated with this research. The study is recruiting participants who are:

- Adults ages 18 and older
- Previously diagnosed with a cancer of the head and neck
- Experiencing dry mouth caused by radiation therapy
- Cancer-free (5 or more years)
- Not pregnant or breast feeding
- Non-smoker

To learn more about the study contact Linda McCullagh, RN, MPH, and include that you were referred by The Oral Cancer Foundation. She can be reached at mccullagh@nidcr.nih.gov. More information may be found at ClinicalTrials.gov and www.drymouthstudy.com.

Adapting the science of supplements and cancer prevention

by: Carmen Phillips

Numerous studies suggest that avoiding excess weight, exercising regularly, and eating a diet heavy on fruits and vegetables decreases the risk of many diseases, including cancer. But as the expanding obesity epidemic has shown, there are major obstacles to getting broad swaths of people to adopt such a healthful lifestyle. So, for many years, cancer researchers have investigated whether specific nutrients—those that epidemiologic and animal model studies have suggested could sway cancer's course—could decrease cancer risk.

Much has been learned from this work, researchers in the field say, but, as is the case with treatment, each new discovery points to new areas of focus and other potential avenues of progress.

With promising bioactive compounds in the pipeline, many prevention researchers are focused on figuring out not just whether something like sulforaphane, a natural compound found in broccoli and broccoli sprouts, can kill cancer cells in a test tube or animal model—which it does, quite well—but how, at the molecular level, it accomplishes this task, whether there are some

24 hrs) GO-GOs (Great Offer-Giving Opportunities), featuring a 50% or higher discount off a product, service or membership at a well-known Chicago establishment. The GO-GO is a perfect solution for gift giving as well as a cost-friendly way to experience the best that Chicago has to offer.

By purchasing goods or offers through We Give to Get, you will be donating to OCF at no additional cost to you. For more information and to help OCF through We Give to Get, visit: WeGivetoGet

"To laugh often and much; to win the respect of intelligent people and the affection of children, to earn the appreciation of honest critics. To appreciate beauty; to find the best in others; to leave the world a little bit better whether by a healthy child, a garden patch, or a redeemed social condition; to know that even one life has breathed easier because you have lived. This is to have succeeded."

- Ralph Waldo Emerson



cancer cells that are more likely to respond to it, and whether there are ways of discerning early on that the intervention is having its intended effect.

Prevention: A Complex Matter

A number of supplements have been tested in large prevention trials, including vitamins A, C, and E; selenium; beta-carotene; and folic acid. At least [one trial](#) has demonstrated a reduction in cancer deaths with a combination of supplements, while several others found no reduction or even a small increased risk.

“There was suggestive evidence in humans” to support the large clinical trials conducted to date, said Dr. Peter Greenwald, director of NCI’s [Division of Cancer Prevention](#) (DCP). Millions of people are taking supplements in the belief that they can improve their health, including preventing cancer, he continued, so getting data from randomized clinical trials—the gold standard of biomedical research—is critical. [Read More...](#)

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