NEWS FROM S•P•O•H•N•C



VOL. 22 NO. 6

SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER, INC.

MARCH 2013



Integrative Oncology – Support for People with Oral, Head and Neck Cancer with Traditional Chinese Medicine

Matthew Enright, AP, DOM

Traditional Chinese Medicine (TCM) is based on traditional medical practices originating in China. TCM stems from the belief that what happens to one part of the body affects every other part of the body. Similarly, organs and organ systems are



viewed as interconnected structures that work together to keep the body balanced and harmonious.

TCM is a complete medical system that recognizes true healing is a multidimensional process. This ancient holistic medical system, understands that the mind, body, spirit and emotions must all be focal points during the healing journey. The mind and the emotions play an influential role in creating wellness or

illness and attracting disease.

All of these aspects and their relationships are mapped out in the theories that form the foundation of TCM: the Theory of Yin/Yang, the Theory of Qi (pronounced *chee*) or vital energy, Meridian Theory and the Five-Element Theory. TCM has used these time-tested theories to understand, diagnose and effectively treat health problems and conditions in continuous practice for thousands of years.

Acupuncture; a modality of Traditional Chinese Medicine (TCM), is the most commonly used system of healing in the world as it is one of the oldest systems of medicine dating back 4,000 years. The theory of acupuncture is based on the aforementioned Qi, the vital force or energy of the human body. According to

TCM, Qi is circulated in all parts of the body via energy channels, meridians or pathways. This energy flow is often compared to the circulatory system and nervous system, however, it should be noted and acknowledged as a separate, complex network of microsystems interconnecting the body. If there is an interruption, blockage or imbalance in the flow of Qi in the meridians, it can lead to pain, illness and disease. Acupuncture restores the balance, thus allowing for the normal flow of Qi throughout the body and restoring health to the mind, body and spirit.

Various factors affect the smooth flow of Qi, such as injury, poor nutrition, organ malfunction or infection by harmful microorganisms etc. Other factors that disturb the balanced flow of Qi are extreme climatic conditions (cold, wind, heat, damp), as well as the emotional state (pleasure, dejection, stress, despair, confusion, fear) and overall health of an individual.

How Does Acupuncture Work?

Acupuncturists will place fine, sterile needles at specific acu-points on the body. The insertion of needles activates the body's Qi and promotes natural healing by enhancing recuperative power and activating the body's innate ability to heal itself. It also can improve overall function and well-being. It is a safe, painless and effective way to treat a wide variety of medical problems and conditions.

When the needles are inserted into specific acu-points, acupuncture triggers direct, measurable effects on the body including the following:

- Improved Circulation
- Reduced Inflammation/Stagnant Heat
- Pain Relief

Improved Circulation

Chinese acupuncture theory maintains that there are 12 main meridians or energy channels that relate to the internal organs: lungs, large intestine, stomach, spleen, heart, small intestine, bladder, kidney, pericardium (the sac around the heart), triple warmer (or san jiao), gall bladder and liver.

Acupuncture is based on the assumption that Qi courses throughout the body through these meridians. An acupuncture treatment works by regulating the movement of Qi, which is responsible for the circulation of blood, so by restoring the healthy circulation of Qi throughout the body, there is a healthy circulation of blood. This improved circulation will also help to accelerate recovery times from invasive procedures by nourishing affected tissues.

Reduced Inflammation

When acupuncture needles are inserted, this triggers a response from the central nervous system to release a substance called

INTEGRATIVE ONCOLOGY continued on page 2

<u>Page 2</u> <u>March 2013</u>



BOARD OF DIRECTORS

Nancy E. Leupold, MA, President & Founder James J. Sciubba, DMD, PhD, Vice President Gail Fass, Secretary Walter E. Boehmler, Treasurer Ralph A. Catalano, Esq. Dorothy Gold, MSW, LCSW-C, OSW-C

EXECUTIVE DIRECTOR
Mary Ann Caputo

MEDICAL ADVISORY BOARD

David M. Brizel, MD
Duke University Medical Center
David W. Eisele, MD, FACS
Johns Hopkins Univ. School of Medicine
Bonnie Martin-Harris, PhD, CCC-SLP
Medical University of South Carolina
Eugene N. Myers, MD, FACS
Univ. of Pittsburgh School of Medicine
David Myssiorek, MD, FACS
New York University
David G. Pfister, MD
Memorial Sloan-Kettering Cancer Center

Jed Pollack, MD
Long Island Radiation Oncology
Karrie Zampini Robinson, LCSW
Fighting Chance, Sag Harbor, NY
David L. Schwartz, MD
(tbd)
James J. Sciubba, DMD, PhD
Greater Baltimore Medical Center
Elliot W. Strong, MD, FACS, Emeritus
Memorial Sloan-Kettering Cancer Center
Everett E. Vokes, MD
University of Chicago Medical Center

Randal S. Weber, MD, FACS MD Anderson Cancer Center

NEWSLETTER EDITOR Chris Leonardis

News From SPOHNC is a publication of Support for People with Oral and Head and Neck Cancer, Inc. Copyright ©2012-2013

DISCLAIMER: Support for People with Oral and Head and Neck Cancer, Inc. does not endorse any treatments or products mentioned in this newsletter. Please consult your physician before using any treatments or products.

IN THIS ISSUE

A Time For Sharing	5
April Awareness Month	
Head and Neck Cancer News	
Local Chapters of SPOHNC	9

INTEGRATIVE ONCOLOGY continued from page 1

"Cortisol". Cortisol is the body's own natural anti-inflammatory and anti-stress chemical. Reducing inflammation helps to promote healing which explains why acupuncture works so well for joint and structural disorders.

Pain Relief

Studies into the physiological reactions of the body following acupuncture treatments have offered some scientific insight into how acupuncture affects pain. The findings focused on the ability of acupuncture to stimulate the production of endorphins, which are the body's natural painkillers and feel good chemicals. Endorphins have been found to be nearly 1,000 times stronger than morphine. MRI research also demonstrates that acupuncture induces several cerebral glucose metabolism changes in pain-related brain regions and reduces intensity of pain.

Treatment for oral, head and neck cancer patients and survivors:

Typically cancers of the head and neck begin in the squamous cells in the mucosal lining inside the head and neck (for example, inside the mouth, the nose and the throat). These squamous cell cancers are commonly referred to as squamous cell carcinomas of the head and neck. While relatively uncommon, cancers of the head and neck can also begin in the salivary glands. There are several types of salivary gland cancers as these glands contain a variety of different types of cells that can become malignant.

The integration of traditional Chinese medicine and Western medicine and their clinical effects has been widely evaluated. Studies have shown that using a combination of both traditional Chinese medicine and Western medicine has resulted in better outcomes versus using only one of them. Acupuncture is a traditional Chinese medical modality, which plays an important role in pain management, functional improvement, overall wellness and prevention.

Acupuncture is currently being used in the treatment of cancer patients for pain management, fatigue, reduction of post-operative and chemotherapy-induced side effects and to increase saliva production in patients suffering from xerostomia (dry mouth) which is commonly experienced by cancer patients following radiation of the head and neck regions. Acupuncture also reduces joint pain and stiffness, reduces stress and improves overall physical and mental well-being in patients. Acupuncture is generally safe, painless and well tolerated by patients. It is noted that particular conditions require continuous treatments in order to achieve long-term effect.

Current research available through Memorial Sloan-Kettering Cancer Center in New York, supports the efficacy of acupuncture in the following areas:

- Acupuncture for the treatment of pancreatic cancer pain
- Acupuncture for hot flashes in breast cancer patients
- Acupuncture for post-thoracotomy pain
- Functional Magnetic Resonance Imaging (fMRI) Changes Associated with salivation following Acupuncture
- Acupuncture for pain and dysfunction after neck dissection, and acupuncture for xerostomia (dry mouth)

INTEGRATIVE ONCOLOGY continued on page 3

Page 3 March 2013

INTEGRATIVE ONCOLOGY continued from page 2

Further research, education and clinical trials are required to continue the validation and integration of acupuncture and integrative oncology treatments in conjunction with conventional treatments currently available.

Post Operative Pain Management:

Acupuncture is most commonly known for its ability to successfully manage pain. Pain is typically an indication, forewarning or a direct result from a problem or condition that exists somewhere in the body. The intensity of the pain (typically measured on a VAS pain scale of 1-10) can usually indicate the severity of the problem and the quality of the pain can also give insight as to the underlying cause of the pain. Typically Acupuncturists will note two types of pain qualities; "dull and achy" or "sharp and stabbing". Dull and achy pain refers to "energy" related pain or Qi stagnation; sharp and stabbing pain refers to blood stagnation or stasis (specific acu-points will be used depending upon the quality of the pain). Both can be helped with local and distal acupuncture treatments which will stimulate a series of reactions along the pain pathway (the previous mentioned phenomena of improved circulation, reduced inflammation and endorphin release). By increasing the blood supply to a post operative area and surrounding tissue(s), acupuncture treatments are able to accelerate the recovery process following surgical procedures and provide short term symptomatic pain relief as well as long term chronic pain relief.

Other factors which also have importance in determining the appropriate treatment protocol would be a specific time of day when the pain is better or worse, whether the pain is affected with climatic changes, or whether the pain is better or worse with ice or heat, movement or rest.

Fatigue:

As noted in a 2004 study by the American Society of Clinical Oncology, Acupuncture for Post Chemotherapy Fatigue: A Phase II Study; Generalized fatigue and chronic fatigue symptoms are often experienced by both cancer patients and cancer survivors. Currently, chronic fatigue is not diagnosed with a specific test nor is there a specific treatment available with conventional medicine. Through a differential diagnosis,

Acupuncturists are able to determine a syndrome or organ system specific cause of the patients' symptoms. The goal of the treatment is to provide the patient with long term relief by addressing the underlying problem and not simply masking the symptom. This is often referred to as treating the "root vs. the branch" or the "core vs. the symptom." While addressing the patient's complaint(s) or disorder(s), symptomatic relief is offered while working on and addressing the root of the problem or core issue(s) to prevent or decrease the likelihood of the symptoms returning.

Typically in TCM, chronic fatigue symptoms and syndromes stem from a deficiency or weakness of Qi. By utilizing acu-points that specifically regulate the movement of Qi and restoring the healthy circulation of Qi and blood throughout the body, patients are able to feel an overall increase in energy, vitality and general well being.

Post Operative & Chemotherapy-Induced Side Effects:

The NIH Consensus Panel on acupuncture in 1997 concluded that there is evidence that acupuncture is effective for adult postoperative and chemotherapy induced nausea and vomiting. Research supports the use of the acupuncture point PC-6 (Neiguan) which is located on the palmar side of the forearm, approximately three fingers above the crease of the wrist, to counteract the adverse flow of Oi which is typically associated with nausea and vomiting. Acu-pressure can be applied to this point by the patient and is often encouraged during treatment to increase the efficacy of the acupuncture treatments and provide patients with relief on their

While multiple acupuncture points can help the overall post operative and chemotherapy-induced side effects, other variables will determine the specific treatment protocols and selected acupuncture points for each individual patient. Although many patients may present with comparable signs and symptoms, treatments, selected acupuncture points and additional therapies warranted can and will vary based on the differential diagnosis performed by the acupuncturist.

Xerostomia:

Xerostomia is the condition of abnormal dryness of the mouth due to decreased secretion of saliva to keep the mouth wet. It is a disheartening condition which can significantly impair quality of life in sufferers. As per the National Cancer Institute, cancers of the head and neck account for approximately 3 percent of all cancers in the United States and their treatment by radiotherapy gives rise to xerostomia in most cases. Cancer patients typically exhibit a high prevalence of xerostomia. According to a 1999 study, roughly 70% of seriously ill cancer patients suffered from xerostomia.

Studies show a significant increase in saliva both during and after acupuncture treatments which involve manual or electrical stimulation. Patients are typically treated with specific acupuncture protocols involving points to calm the mind, reduce inflammation and hypersensitivity, increase saliva and additional support to other acu-points based on symptom variables. Treatments include both body acupuncture and auricular (ear) acupuncture. Acupressure treatments may also be included in the patients' treatment plan as this will allow patients to treat themselves while not in the office in an effort to maximize treatment efficacy and results.

Studies also show improvement with saliva output in patients that are given sugarless mints during treatment to help stimulate salivary flow, although the mints usually produced little, if any, saliva without the use of acupuncture. In 2011, a randomized controlled trial of acupuncture for prevention of radiation-induced xerostomia among patients with nasopharyngeal carcinoma showed that acupuncture given concurrently with radiotherapy significantly reduced xerostomia and improved quality of life. Cancer, 118: 3337–3344.

Patients are usually treated once or twice a week for six to eight weeks with continued treatments as necessary. The number of treatment sessions will vary from patient to patient dependent upon other variables with which the patient may be dealing (insomnia, digestive disorders, emotional strains and stressors etc.) In certain instances, increase in salivary flow can be seen as soon as the first visit and the duration of improvement typically

INTEGRATIVE ONCOLOGY continued on page 4

Page 4 March 2013

INTEGRATIVE ONCOLOGY continued from page 3

increases as the treatments continue, while other patients may need several treatments to receive an improvement. The focus of the treatments is to get patients into what is known as the "wellness phase" where the patient's protocol will be dictated by how the overall patient response is. Meaning, once the patient reaches this wellness phase, if they feel good for 15 days, we want to see them in 15 days, if the patient feels good for 30 days, we want to see the patient in 30 days etc., ultimately coming in for treatments and follow ups for overall maintenance and well being.

Editors Note: Matthew Enright, AP, DOM (FL) is a Diplomate in Oriental Medicine and currently practices acupuncture in Manhattan and Long Island, New York. Certified in advanced acupuncture for Cancer Patients -Integrative Oncology from Memorial Sloan-Kettering Cancer Center, Integrative Medicine Service, Matthew also received his first Degree Reiki Certification from The Reiki System of Natural Healing. He is also an adjunct professor at NOVA Southeastern University teaching Integrative Medicine and the fundamentals of Traditional Chinese Medicine in the Bachelor of Health Sciences program and is also adjunct faculty and an acupuncture consultant for the University Of Miami, Miller School of Medicine.

SPOHNC has designated

APRIL

ORAL AND HEAD
AND NECK
CANCER
AWARENESS MONTH

Are you, or your chapter, interested in hosting an Awareness or Taste Event?

SPOHNC can help you.

To find out more, contact SPOHNC at 1-800-377-0928, or e-mail us at info@spohnc.org

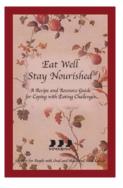
Already planning your Awareness Event, Screening, Taste Event or Walkathon?

Let us know so we can share it with our many readers, and post it on our website at www.spohnc.org

MEETING THE CHALLENGES OF ORAL AND HEAD AND NECK CANCER A GUIDI FOR SURVIVOUS AND CAMEOVIES Namey E. Leupold James J. Sciubba

The Second Edition featuring 5 New Chapters, Updated Information, Product Resources \$27.00 Includes postage

Now available directly through SPOHNC at www.spohnc.org or by calling us at 1-800-377-0928



Eat Well – Stay Nourished: A Recipe and Resource Guide for Coping with Eating Challenges \$20.00 Includes postage

> www.spohnc.org 1-800-377-0928

News From The Board Room

SPOHNC would like to welcome the



newest member of our Board of Directors. Dorothy Gold, MSW, LCSW-C, OSW-C is senior oncology social worker at The Milton J. Dance, Jr. Head & Neck Center, where

she works with head and neck cancer patients and their families. Dorothy received her Masters in Social Work from the University of Maryland and has over

30 years of experience in the field of social work, primarily in medical and oncology settings. She is Board Certified as an oncology social worker and was recognized in 2010 as Oncology Social Worker of the Year by the Association of Oncology Social Work. Dorothy is also a field instructor for the University of Maryland School of Social Work. Dorothy has clinical and research interest in quality of life and psychosocial adjustment for head and neck cancer patients and has presented locally and nationally on this subject. Dorothy is also the Facilitator of the SPOHNC Baltimore GBMC Chapter support group.

Page 5 March 2013

A TIME FOR SHARING...Living My Life

In the last 10 years, I have had four head and neck surgeries for malignant tumors, two courses of head and neck radiation, and one lung surgery to remove two nodules which turned out to be benign. I had two face and neck reconstruction surgeries, too, and 30 hyperbaric oxygen treatments for a broken jaw due to osteoradionecrosis. But it is the details of the first surgery that stick in

my mind.



In my Philadelphia hospital, they allowed me to walk with my wife Susan from the prep area to the elevator for

the ride up to pre-op. The nurse escorted us. I pulled along the wheeled stand that had my IV bag swinging to the rhythms of our steps. I held Susan's hand and assured her that everything would be ok. She was allowed to come with me into the elevator. When we arrived at the O.R. floor, though, she had to stay put. I kissed her and walked out of the elevator and turned right toward the doors to pre-op, pushing the IV pole along. I heard the elevator doors close behind me and, for the first time, I was filled with fear. I felt scared and alone. I choked up. But I pulled myself together by thinking, "It's O.K. It's time. This is right. Do this." The nurse opened the doors to pre-op and I walked in. I climbed onto a gurney and became another sheeted figure in a room full of sheeted figures, each with an IV tree standing nearby like a stainless-steel sentinel. I awaited my turn...

That was in November, 2002. About three years before this event, my internist, whom I saw annually for a physical, was so concerned about my lively drinking and smoking lifestyle (even though I had quit both in 1995) that he recommended an otorhinolaryngologist for me to see twice a year. He knew I had the classic profile for head and neck cancer. And so began my long relationship with the head and neck surgeon who saved my life numerous times.

In January 2002, one of my adult sons died unexpectedly. It broke my heart and my Susan's too. It changed things forever.

My internist told me that carrying a heavy burden of grief can sometimes stress the human system in difficult ways and he encouraged me to be especially vigilant for anything going wrong in the coming months.

In the spring, around the time of my 61st birthday, I found two swollen lymph nodes in my left neck. My surgeon needle biopsied both and found that the swelling was caused by infection. He prescribed a course of powerful antibiotics and the swelling subsided. But that summer, I never really felt well. It was as if I had a low grade fever. My energy was sagging. In October, the two nodules swelled up again and open biopsy was recommended.

The November 2002 surgery was fairly straight forward. The surgeon removed the nodules, and while I was still open, they found that the infections in both of them were encased in malignant cells. The needle biopsy had pierced through the shells and extracted only infected material – missing the malignant cells in the casing around the nodules. With this information in hand, he continued the surgery by removing a dozen nearby lymph nodes to make sure the area was clear of cancer. Then he sewed me up: a neat, now barely visible, six inch scar on the left side of my neck. The diagnosis was squamous cell cancer of unknown origin.

Thirty radiation treatments were recommended and I completed them on January 31, 2003. I was asked if I wanted to have a feeding tube inserted because the inside of my mouth would be burned and irritated by the radiation. I said no, and for weeks I ate nothing but a liquid product called Resource 2.0, which provides perfect medical nutrition. I lost my sense of taste, and for a few months I ate no solid food other than ice cream and scrambled eggs and smoothies. It hurt to swallow anything and everything. Many of you readers know the drill. It was, I am told, a very heavy dose of radiation. The fatigue I experienced for months after the treatment was unlike anything I had known before.

That spring of 2003 my energy was limited, but I had an idea for a good project. My wife and I bought a deteriorating 30 year old 19' sailboat which needed work. We named her Moonshadow. And while I lacked

the wellness to be on my feet working for hours, I found that I could work quite well on my hands and knees: sanding, painting and varnishing. I had never done anything like this before. It's amazing what you can learn by reading the directions on cans of paint and varnish. It gave me a real sense of purpose and accomplishment and made me feel alive. How I loved Moonshadow. She was beautiful when she was finished and I sailed her every minute I could that summer.

The burns in the lining of my mouth and my esophagus healed in about six to eight months. It is odd how that happens. The eating disabilities diminished so slowly that I often did not recognize how much progress I was making. One day late in the summer I realized I was pretty close to normal again. My energy was much better and I knew that some working out would get me back to where I had been. It was still hard to tolerate hotly spiced food, but otherwise I knew that I had recovered well. My sense of taste was back. I could swallow solid food with only occasional difficulty by lubricating it with water. Meat was always difficult though, so I gave it up. I was already used to carrying a water bottle with me to help with the dry mouth and I was eating a fairly healthy diet.

I was cancer free for what seemed a long time except that I had many early stage skin cancers removed. It reminded me that all of those wonderful shirtless, shoeless summers I spent along the Toms River in New Jersey when I was a boy may not have been quite as healthy as my mom thought. But I did learn to sail a little 8' boat and that led me to Moonshadow later on. What a great gift from those summers.

Three years after that first surgery, I was diagnosed with a squamous cell tumor on the right side near the parotid gland. Surgery was scheduled for December 23, 2005. This surgery included a partial parotidectomy. The diagnosis was the same: squamous cell cancer of undetermined origin. No further therapy was recommended and recovery was less arduous. But I had a greater saliva deficit because my parotid was partially gone. I knew what to do about that. Never forget to bring the water bottle.

Sometime just prior to this second

Page 6 March 2013

surgery, I decided to estimate what percentage of each day I must give to the business of being a cancer patient. On the first day out of surgery I was 100% a patient and too groggy and too much in pain to do anything except submit to medical care. But on the second day, I noticed that I was a patient only 95% of the time - the 5 % being given to communication with friends and family. I loved doing this. On the third day, I was released and went home. What a joy it was to be among all my familiar things. I talked with my wife Susan about cancer and non-cancer stuff, read a little, made my own coffee, watched favorite shows on TV and took short, slow walks around the apartment. Sleeping during the day was frequent, but I felt that I had made the leap to being only 80% a patient and 20% a man leading his life. With each day, the percentage changed and it was always moving in the right direction.

All of that was interesting to me. And it was good. But it didn't really answer the question of how I was going to deal with the permanent damage and side effects of surgery and subsequent radiation. Simply put, the visible damage to my face and neck, as well as damage unseen by others, was part of me now and that would not change. I hated these things. How would I live with them? I learned that if I spent too much time obsessing over this I would be moving the percentages in the wrong direction. So I arrived at the place where I decided that I would give cancer treatment and recovery and side effects no more of the precious time I have in this life than is absolutely necessary. This involved learning to stay in the present. If I thought too much about the past or the future, I found that my attitude began to deteriorate and I would be giving more time to cancer than it deserved. I needed to stay in the present and lead a full life.

I read a book by Roz Savage called *Rowing The Atlantic*. Reading about her mental and physical struggles as she rowed for 103 days unassisted across the Atlantic Ocean helped me to understand how to accommodate the physical and emotional damage of cancer surgery and radiation. She isolated her most harsh and difficult physical and emotional challenges into a zone in her own mind that she called her discomfort zone. And once she isolated the

elements that made up her discomfort zone, she could greet these things daily as old acquaintances, curse them roundly, and get on with the business at hand. Her physical and emotional scars became symbols of her toughness. By that odd mental trick, she made the discomfort zone part of her daily comfort zone.

The elements in Roz Savage's discomfort zone became the spark and the fuel for her perseverance. That fire enabled her to avoid a failure of the spirit. And that is what I try to do.

Five months later, in early May of 2006, I had a squamous tumor removed from the right side and it was very involved with the parotid gland again. He removed the remainder of the parotid and the tumor and more lymph nodes in the area. Further therapy included 31 radiation treatments in August 2006, mostly slanting just under the surface of the skin. The conclusion had been reached that the cancer cells likely came from my many skin cancers and that some malignant cells probably hide in the dermal lymphatic system.

In between the surgery and the radiation, with two friends whom I had taught to sail, I chartered a 40' sloop in the British Virgin Islands and we sailed her for a week. I skippered. They did the heavy work. What a great experience. We vowed to do it every two years. And we do that.

I had the radiation treatments in August after the charter. But it turned out the radiation didn't do the trick. On February 9, 2007, two more squamous cell tumors were removed from cervical lymph nodes on the right side of the neck by radical neck dissection. Reconstructive surgery was necessary and they used muscle and tissue from the right side of my chest. Because they wanted to keep the vascular system intact, they moved the whole business up over my collarbone and used it to close the wound in my neck.

One month later, at the end of March, 2007, two nodules thought to be malignant were removed from my right lung. To everyone's surprise, they were benign. I was mighty pleased.

As I was recovering in the early summer of 2007, a friend of mine put me into his rowboat on Toms River and said, "You can do this." I fell for it. In the fair weather I now row 7 or 8 miles a day. I have rowed

hundreds of miles. It's like a meditation for me

In 2009 Susan and I organized a sailboat charter on the Croatian coast with two other couples and we sailed the boat from Split through the hundreds of offshore islands in the Adriatic and ended our cruise in Dubrovnik. Ulysses had sailed through these islands many hundreds of years ago. We had a fabulous time.

As I write this I am 71 years old. I have not had a major surgery since 2007. My side effects are numbness and partial paralysis on the right side of my face, some swallowing difficulties, dry mouth, disfigurement, nerve damage affecting my right eye and my right shoulder, and osteoradionecrosis of the right mandible which has given me a broken jaw. I can live with it all. I do live with it all. I have a good life.

This past summer (2012) I was laid low for several months by a nasty kidney disease. While rowing and sailing on the Toms River, I had increasingly seen people on the river using stand-up paddleboards. I bought one and threw it into the garage to try when I was feeling better. While I was laid up, I used YouTube to teach me how it is done. In August I began using it. What a kick. I feel like a Samoan warrior when I am out on it.

I know that I am an optimist and that not everyone is. And I know that if one is a pessimist cancer will not turn them into an



optimist. So what I have written here may not be for everyone. But maybe there is

just one thing in here that will help someone. That would be a good outcome.

I just try to get the best out of every day. Also, I attempt to stay fearless about trying new things. All of this has been made possible by superb medical care in Philadelphia. And most importantly, I stay devoted to my dear wife of 42 years, Susan. Without her loving help my passage would have been through much stormier seas.

Bob Brecht brechtbob@gmail.com

Page 7 March 2013

HEAD AND NECK CANCER NEWS

New Drug Combination Could Prevent Head and Neck Cancer in High-Risk Patients

PHILADELPHIA — A new drug combination shows promise in reducing the risk for patients with advanced oral precancerous lesions to develop squamous cell carcinoma of the head and neck. The results of the study, which included preclinical and clinical analyses, were published in Clinical Cancer Research, a journal of the American Association for Cancer Research.

"Squamous cell carcinoma of the head and neck (SCCHN) is the most common type of head and neck cancer," said Dong Moon Shin, M.D., professor of hematology, medical oncology and otolaryngology at Emory University School of Medicine, and director of the Cancer Chemoprevention Program at Winship Cancer Institute at Emory University in Atlanta, Ga. "The survival rate for patients with SCCHN is very poor. An effective prevention approach is desperately needed, especially since we can identify patients who are at extremely high risk: those with advanced oral precancerous lesions."

Based on prior research suggesting a role for epidermal growth factor receptor

(EGFR) and cyclooxygenase-2 (COX-2) in promoting SCCHN, Shin and colleagues believed combining an EGFR inhibitor and a COX-2 inhibitor could provide an effective chemopreventive approach.

They found that the combination of the EGFR inhibitor erlotinib and the COX-2 inhibitor celecoxib was more effective for inhibiting the growth of human SCCHN cell lines compared with either drug alone. In addition, treating mice with the drug combination prior to transplanting them with human SCCHN cells more effectively suppressed cancer cell growth than did pretreating the mice with either drug alone.

Based on these preclinical analyses, Shin and colleagues initiated a phase I chemoprevention trial. Eleven patients with advanced oral precancerous lesions were assigned to treatment with erlotinib and celecoxib. Tissue samples from the patients were obtained and evaluated pathologically at three, six and 12 months after therapy initiation. Biopsies at baseline and follow-up were available for seven patients.

Pathologic examination of the biopsies indicated that three of the seven patients had a complete pathologic response; that is, there was no longer evidence of the precancerous lesions in the follow-up biopsy sample. Among the other patients, two had a partial pathologic response and two had progressive disease.

"Finding that this drug combination caused some advanced premalignant lesions to completely disappear was great news," said Shin. "Advanced premalignant lesions rarely regress, so our data are proof-of-principle that a combination chemopreventive strategy with molecularly targeted agents is possible."

Several patients dropped out of the trial because of severe adverse side effects, according to Shin. "Prevention is not achieved through short-term treatment," he said. "So, we need to investigate the safety and toxicity of this combination further before planning a large-scale trial. We are also looking to combination therapies using less toxic or nontoxic agents, such as natural compounds."

###

APRIL AWARENESS MONTH

SPOHNC has designated the month of April as Oral, Head and Neck Cancer Awareness Month. Our Annual Awareness Campaign includes taste events, oral cancer screenings, walkathons and several other events, to be hosted by many of our 120 plus SPOHNC Chapters across the United States. We hope that everyone will participate by helping to promote awareness in some way.

If you are planning or participating in an event, please let us know. We'd like to feature your story in an upcoming issue of our newsletter, *News from SPOHNC*, and also on the website at www.spohnc.org. Past events have included not only Taste Events and screenings, but also potluck luncheons and dinners, walk-a-thon, bike-a-thons, skate-a-thons and even ice cream socials! Some of these unique ideas are featured on our website, so visit us at www.spohnc. org to see what others have done.

Important because they can help to raise awareness of oral, head and neck cancers, these events have also supported SPOHNC as we continue to provide all of our excellent programs and resources to patients, caregivers, survivors and family members. Our SPOHNC Chapter Support Groups, the National Survivor Volunteer Network match program, resource guides



and this newsletter are all part of the support services that we have been offering to oral, head and neck cancer patients for over 20 years.

Please share this information with your family, friends and healthcare professionals. If you are a member of a SPOHNC Chapter support group, why not consider hosting an event with your group? Events do not have

to be held in April - they can be held at any time of the year. Promoting awareness is the key, no matter when it happens.

What kind of creative idea can you come up with to help raise awareness in your community? We hope you will join us this year. If you have an idea for an event but you're not sure how to get started, call us at 1-800-377-0928. SPOHNC can connect you with others who have run a successful awareness event.

We value your help in raising awareness of oral and head and neck cancer.

Remember – we can all make a difference if we work together.



has matched more than 1,000 patients and survivors through the NSVN match program?

Page 8 March 2013

SURVIVOR NEWS

Ronnie Trentham, six-time head and neck cancer survivor, and member of the Fayetteville, AR SPOHNC chapter, celebrated his fifth year of being cancer-free by welcoming his first grandchild into the world in September of 2012. During his six different battles with cancer, Ronnie sometimes won-



and the Lord he dered if he would ever get to experience the joys of being a grandparent. To him, Ronnie's granddaughter, Lily Kate is one more of the reasons he never gave up in his fight against oral, head and neck cancer. He wanted to be alive to spoil his grandchildren, and that is exactly

what he is doing with Lily. Ronnie also credits the encouragement and support he received from organizations like SPOHNC and the American Cancer Society in helping him to beat cancer. He is so proud to be a "Papa" and loves to babysit. Ronnie is looking forward to more grandchildren in the future and being here to teach them that sometimes life is hard but it is also filled with wonderful things that make never giving up so very worth the fight!

An Old Irish Blessing

May love and laughter light your days, and warm your heart and home. May good and faithful friends be yours, wherever you may roam. May peace and plenty bless your world with joy that long endures. May all life's passing seasons bring the best to you and yours!

HEAD AND NECK CANCER NEWS

UNC-led study documents head and neck cancer molecular tumor subtypes

CHAPEL HILL, N.C. - Head and neck squamous cell carcinoma (HNSCC) is the seventh most common form of cancer in the United States, but other than an association with the human papillomavirus, no validated molecular profile of the disease has been established. By analyzing data from DNA microarrays, a UNC-led team has completed a study that confirms the presence of four molecular classes of the disease and extends previous results by suggesting that there may be an underlying connection between the molecular classes and observed genomic events, some of which affect known cancer genes. The clinical relevance of the classes and certain genomic events was demonstrated, thus paving the way for further studies and possible targeted therapies. The study was published in the Feb. 22, 2013 issue of the journal PLOS ONE.

Neil Hayes, MD, MPH, associate professor of medicine and senior author, says, "Cancer is a disease caused by alteration in the DNA and RNA molecules of tumors. A cancer results when broken molecules initiate a cascade of abnormal signals that ultimately results in abnormal growth and spread of tissues that should be under tight control within the body.

"However, most common tumors, including head and neck cancer, have relatively little information in the public record as to how these signals coordinate to create different patterns of abnormalities. This study is among the largest ever published to document reproducible molecular tumor subtypes. Subtypes, such as those we describe, represent attractive models to understand and attack cancers for treatment and prognosis."

Dr. Hayes is a member of UNC Lineberger Comprehensive Cancer Center and national co-chair of the Data Analysis Sub-Group for The Cancer Genome Atlas, a program of the

National Institutes of Health.

The team, composed of investigators from UNC and five other institutions, analyzed a set of nearly 140 HNSCC samples. By searching for recurrent patterns known as gene expression signatures, they were able to detect four gene expression subtypes. The subtypes are termed basal, mesenchymal, atypical, and classical based on similarities to established gene expression subtypes in other tumor types and expression patterns of specific genes.

In spite of being the seventh most common form of cancer in the United States, HNSCC is relatively under-studied in comparison to other tumor types, e.g. breast and lung. By leveraging the similarities found in the gene expression subtypes, the results of this study provide a connection to a range of well-established findings and additional insight into the disease.

###

Coming Soon... Eat Well - Stay Nourished Volume Two

Some Eating Tips from Volume One:

- 1. Add gravies and sauces, applesauce or other liquids to foods.
- 2. Have a spoonful of warm liquid such as soup between mouthfuls of food.
 - 3. Drink through a straw to bypass mouth sores.
- 4. Ask your physician about artificial saliva.
 - 5. Use plastic utensils instead of silverware, to reduce metallic taste.

"Like" SPOHNC on Facebook

CHAPTERS OF SPOHNC
Contact SPOHNC at 1-800-377-0928 for Chapter information & Facilitator contact information

ALABAMA-BIRMINGHAM	COLORADO-PUEBLO	FLORIDA-OCALA	
ARIZONA-CHANDLER	CONNECTICUT-NEW HAVEN	FLORIDA- PALM COAST/ NORTHEAST FLORIDA-SARASOTA FLORIDA-TAVARES	
ARIZONA-PHOENIX/MESA	CONNECTICUT-NEW LONDON		
ARIZONA-PHOENIX	CONNECTICUT-NORWICH		
ARIZONA-SCOTTSDALE	DC-GEORGETOWN	FLORIDA-W. VOLUSIA COUNTY (ORANGE CITY)	
ARKANSAS-NORTHWEST	FLORIDA-BOCA RATON	GEORGIA-ATLANTA	
CALIFORNIA-LOS ANGELES-UCLA	FLORIDA-FT MYERS	GEORGIA-ATLANTA-EMORY	
CALIFORNIA- NEWPORT BEACH	FLORIDA-FTWALTONBEACH/NW FL	GEORGIA-AUGUSTA	
CALIFORNIA-ORANGE-UCI	FLORIDA-GAINESVILLE	GEORGIA-COLUMBUS	
CALIFORNIA-SAN DIEGO	FLORIDA-JACKSONVILLE	ILLINOIS-CHICAGO	
CALIFORNIA-SANTA MARIA	FLORIDA-JACKSONVILLE	IL-EVANSTON/HIGHLAND PARK	
CALIFORNIA-STANFORD	FLORIDA-LECANTO	ILLINOIS-MAYWOOD	
CALIFORNIA-VENTURA	FLORIDA-GREATER MIAMI	INDIANA-FORT WAYNE	
COLORADO-COLORADO SPRINGS	FLORIDA-MIAMI/DEERFIELD BEACH	INDIANA-INDY-NORTH	
COLORADO-DENVER	FLORIDA-NAPLES	INDIANA-INDY-WEST	

http://www.spohnc.org

E-mail-- info@spohnc.org

S•P•O•H•N•C

CHAPTERS OF SPOHNC
Contact SPOHNC at 1-800-377-0928 for Chapter information & Facilitator contact information

INDIANA-SOUTH BEND	MINNESOTA-MINNEAPOLIS	NEW YORK-MANHATTAN/NYU	
INDIANA-TERRE HAUTE	MISSOURI-ST. LOUIS	NEW YORK-MANHATTAN/MT. SINAI	
IOWA-DES MOINES	MONTANA-BOZEMAN	NEW YORK-MIDDLETOWN	
KANSAS-KANSAS CITY	NEBRASKA-OMAHA/MCC	NEW YORK-NEW HYDE PARK	
LOUISIANA-BATON ROUGE	NEBRASKA-OMAHA/NMC	NEW YORK-ROCHESTER	
MAINE-AUGUSTA/CENTRAL	NEW JERSEY-LONG BRANCH	NEW YORK-STONY BROOK	
MARYLAND-BALTIMORE-GBMC	NEW JERSEY-MORRISTOWN	NEW YORK-SYOSSET	
MARYLAND-BALTIMORE-JHMI	NEW JERSEY-PRINCETON, UMC	NEW YORK-WESTCHESTER	
MARYLAND-LIBERTYTOWN	NEW JERSEY-SOMERVILLE	NORTH CAROLINA-ASHVILLE	
MASSACHUSETTS-BOSTON	NEW JERSEY- SPARTA	NORTH CAROLINA- DURHAM/CHAPEL HILL	
MASSACHUSETTS-CAPE COD	NEW JERSEY-TOMS RIVER	NORTH CAROLINA-CHARLOTTE	
MASSACHUSETTS MID-CAPE ON CAPE COD	NEW MEXICO-ALBUQUERQUE	OHIO-CINCINNATI	
MASSACHUSETTS-DANVERS	NEW YORK-ALBANY	OHIO-CLEVELAND	
MASSACHUSETTS-NEWTON MICHIGAN-ST. JOSEPH	NEW YORK-BUFFALO	OHIO-DAYTON	
	NEW YORK-MANHATTAN/BIMC	OHIO-LIMA	

S•P**•**O**•**H**•**N**•**C

CHAPTERS OF SPOHNC

Contact SPOHNC at 1-800-377-0928 for Chapter information & Facilitator contact information

OKLAHOMA-TULSA	SOUTH CAROLINA- OF THE UPSTATE	VIRGINIA-CHARLOTTESVILLE
		VIRGINIA-FAIRFAX
OREGON-MEDFORD	SOUTH DAKOTA-RAPID CITY	
		VIRGINIA-NORFOLK
PENNSYLVANIA-DUNMORE	TENNESSEE-CHATTANOOGA	
		VIRGINIA- RICHMOND
PENNSYLVANIA-HARRISBURG	TENNESSEE-NASHVILLE	
		WASHINGTON-SEATTLE/EHMC
PENNSYLVANIA-MONROEVILLE	TEXAS-DALLAS/BIMC	Wilding Office Services
		WA CHINGTON OF APPRICATO
PENNSYLVANIA-NEW CASTLE	TEXAS-DALLAS/BSCC	WASHINGTON-SEATTLE/SMC
PENNSYLVANIA-PHILADELPHIA/TMT	TEXAS-FORT WORTH	WISCONSIN-MADISON
PENNSYLVANIA-PHILADELPHIA/HUH	TEXAS-McALLEN	WISCONSIN-EAU CLAIRE
PENNSYLVANIA-YORK	TEXAS-PLANO	WISCONSIN-MILWAUKEE

SPOHNC Chapter Group Member Testimonial...

"I just wanted to let everyone know who was there today at our monthly meeting what it meant to me. It was so great. To learn new things about nutrition and to laugh a bit!!!! I haven't been out of the house much... so today was special just to be with old and new friends!!!!!! Thanks to you all."

~ Dave N.

ATTENTION!

SPOHNC Chapter Facilitators -

If your meeting location, day and time, or contact information has changed, please be sure to let us know.

Call SPOHNC at 1-800-377-0928, x2 or e-mail us at info@spohnc.org.

SPOHNC Chapter Facilitator Testimonial...

"Being part of SPOHNC and facilitating our local head and neck cancer support group in Nashville is a great blessing to me. It has been an incredibly humbling, rewarding, and inspiring experience. I have learned so much about oral, head & neck cancer, but more importantly I have learned so much about life and living! I am honored to be even a small part of helping people cope with head and neck cancer."

~ Carmin B.



SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER P. O. BOX 53 LOCUST VALLEY, NY 11560-0053

ADDRESS SERVICE REQUESTED

NON-PROFIT ORGANIZATION U.S. POSTAGE PAID LOCUST VALLEY, NY PERMIT NO. 28

SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER (SPOHNC)

SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER, INC. **WEMBERSHIP APPLICATION**

Membership includes subscription to eight issues of News From SPOHNC

CONTRIBUTIONS		KSHIP	T MEMBE		J
		wewper.	gniminsA _		First time memb
		Health Professional (Specialty)	Friend	ioviviuR	Реазе Сћеск:
	qi <u>Z</u>	State			City
					Address
	Address_	lism3			Address
					Лате

□ Booster, \$25+ □ Donor, \$50+ □ Sponsor, \$100+

☐ Leaders Circle, \$10,000+ ☐ Patron, \$500+ ☐ Benefactor, \$1,000+ ☐ Founder, \$5,000+

☐ \$35.00 Foreign (US Currency) Virmet 00.08\$ 🗖 leubividai 00.84\$

to become a member and make a contribution by credit card or order online at www.spohnc.org Call 1-800-377-0928