

NEWS FROM S·P·O·H·N·C



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

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S·P·O·H·N·C
A PROGRAM OF SUPPORT
FOR
PEOPLE WITH
ORAL AND
HEAD AND NECK CANCER

A Novel Imaging Technology to Study Lymphedema in Head and Neck Cancer Patients May Improve Quality of Life for Survivors

Ronald J. Karni, MD

Medical centers that treat a high volume of head and neck cancer are identifying some positive trends relating to the incidence and treatment outcomes of this disease entity. Commensurate with the decrease in smoking, the incidence of larynx cancer is decreasing. And despite a rising incidence of HPV-related tumors of the tonsil and tongue base, these tumors have a remarkably distinct and favorable survival over other sites of head and neck cancer. This has led to an increasing number of head and neck cancer survivors, and an opportunity to look scrutinizingly at the issues of head and neck cancer survivorship.



Nearly all head and neck cancer survivors will have undergone an intense combination of surgery, chemotherapy, and/or radiation therapy in order to achieve a cure. But these treatments, and the cancer itself, are also destructive inasmuch as both short term and long term consequences are experienced by the patient. In the modern era of head and neck cancer, the problems that our patients suffer are myriad – trouble swallowing, voice changes, airway edema (or swelling), neck swelling, muscular scarring and stiffness and decreased range of motion.

Many of these problems can dramatically alter quality of life in survivors. It is not uncommon to see a patient two years after the completion of therapy, and despite evidence of a cure, head and neck cancer patients are often unable to recapture many aspects of

their previous lives. In many instances, the physician may look at the patient and remain bewildered, thinking: “Gosh, I am delighted that we were able to get a cure in this patient despite the advanced stage of his tumor.” However, patients see this differently, as they are commonly still struggling with the side effects of treatment: “Yes, I am thankful to be alive and disease-free, but I am still struggling with every meal to swallow.” It is this Mars-Venus phenomenon that captures the problems of survivorship.

Survivorship in head and neck cancer is also often understudied. Patients will seek out the help of their physicians, speech and occupational therapists, dietitians, chiropractors, and alternative medical therapies in dealing with these side effects. All too often, there are limited options for the management of these side effects. There are few papers in the medical literature dealing with the comprehensive management of side effects of treatment. Physicians are often helpless in providing further direction in these situations, and patients are left to navigate these problems independently.

Many of the problems related to head and neck cancer survivorship can be traced to a little-known phenomenon called lymphedema. Lymphedema can be described as a traffic jam along the highway of lymphatic vessels. Lymphatic vessels exist throughout the body and display very rich networks transporting immune molecules and other substances, all flowing towards the chest. Unfortunately, it is along these same networks that cancer often progresses from a primary site to a lymph node.

When cancer infiltrates a lymph node, the normal architecture of the lymphatic flow through this lymph node is interrupted. Surgery such as a modified radical neck dissection will actually remove the affected lymph nodes as well as normal lymph structures in the vicinity. And while there are few side effects of surgery alone as it relates to lymphatic structures, (and no known effects on the local immune system), it is radiation therapy that often creates a significant amount of side effects. Radiation therapy is very successful when applied to cancer traveling into and through lymphatic structures of the neck and is often the mainstay of treatment in metastatic disease to the neck lymph nodes. However, radiation therapy causes significant interruption of lymphatic flow and is the single most important cause of lymphedema in head and neck cancer patients.

When lymphedema occurs, lymphatic fluid is virtually trapped. Over time, it has been shown by our study group and others that a process of lymphangiogenesis occurs, wherein new routes are formed to mobilize lymphatic fluid. Flow along these routes can be encouraged through a variety of decongestive therapies, performed by specialized lymphedema physicians. However, because of the haphazard nature of lymphangiogenesis, there has arisen a need to identify with medical imaging the erratic layout of new lymphatic structures in order to guide decongestive therapy. Our research group at Memorial-Hermann Texas Medical Center/University of Texas

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Chris Leonardis

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Medical School at Houston, has recently been awarded a grant to study lymphangiogenesis in Head and Neck Cancer patients. This is the first study of its kind, allowing scientists to work alongside cancer practitioners and lymphedema experts in the identification of lymphatic changes over the course of cancer treatment and recovery.

**Improving Survivorship in Head and Neck Cancer:
 UTHealth Department of Otorhinolaryngology
 and Institute of Molecular Medicine
 Partner on CPRIT Research Award**

A \$605,425 grant from the Cancer Prevention Research Institute of Texas (CPRIT) will enable researchers at The University of Texas Health Science Center at Houston (UTHealth) to adapt night-goggle technology used by the military to visualize the workings of the lymphatic system in head and neck cancer patients. The grant was awarded to principal investigator Eva Sevick, PhD, professor of molecular medicine and Kinder Chair at UTHealth’s Institute of Molecular Medicine (IMM). At the IMM, Dr. Sevick leads one of four National Cancer Institute Centers for Translational Research, which focuses on new imaging instrumentation, algorithms and imaging agents and their clinical translation. Ron J. Karni, MD, assistant professor in the department of Otorhinolaryngology-Head and Neck Surgery, and I-Chih Tan, PhD, research engineer at the IMM, are co-investigators for the clinical trial.

“Adapting infrared night-goggle technology in a new way is allowing us to visualize things we’ve never before seen in either animals or human beings,” Dr. Sevick says. “We thought, ‘Eureka! We’re actually seeing the workings of the lymphatic system in living beings.’ Based on what we discover in the clinical trial, we’re hoping to be able to cure head and neck cancer in a more efficient way that improves the overall quality of life of patients.”

Following treatment for their disease, 50 percent of head and neck cancer patients suffer profound lymphedema, swelling due to blockage of the lymph vessels that drain fluid from tissues throughout the body and allow immune cells to travel where they are needed. “During treatment for head and neck cancer, the lymphatic system receives three types of injuries,” says Dr. Karni, who specializes in transoral robotic surgery (TORS) for the treatment of head and neck cancer. “The first is caused by the tumor itself, which infiltrates the lymph system and impedes circulation. Surgery to remove all the lymph nodes in the neck is an assault on the body. The third injury is radiation. Almost all patients with advanced head and neck cancer receive radiation therapy, which seals the lymphatics. Patients undergoing treatment for head and neck cancer usually have fibrosis, very limited movement of the head and neck and lymphedema, which causes debilitation and deformity. We don’t know exactly why the lymph vessels stop pumping, and we hope to gain new information during the course of the study.”

Dr. Sevick has pioneered the development of near-infrared (NIR) fluorescence optical imaging and tomography for molecular imaging. Her research team is active in preclinical small animal imaging with nuclear and optical techniques and is pioneering diagnostic imaging for nodal staging in cancer. For the CPRIT-funded study, she and Dr. Tan took night-goggle technology and developed it into a detector – a

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very small device that uses a charge-coupled device (CCD) chip similar to the chip in a digital camera. Dr. Sevick has pioneered the development of NIR fluorescence optical imaging and tomography for molecular imaging. They have also been developing new dyes that fluoresce.

“Near-infrared light propagates through several centimeters of tissue,” she says. “It’s non-ionizing with no exposure to radioactivity. If we inject a tiny bit of fluorescent dye, it’s taken up by the lymphatic system, allowing us to see the lymph vessel segments that pulse in real time as they pump lymph through the body as little ‘lymph hearts.’”

Dr. Sevick and Dr. Karni note that head and neck cancer survivorship issues have been overlooked until recently. “As we become more efficient at curing cancer, we have to start looking at the aftermath of treatment,” Dr. Sevick says. “Our patients are cured, but living with lymphedema is very expensive, and often they don’t know where to go for help.”

The Memorial Hermann Wound Care Center at Memorial Hermann-Texas Medical Center, under the direction of hyperbaric medicine specialist Erik Maus, MD, operates a Lymphedema Management Center to treat patients with chronic and acute non-healing wounds. The Center also has a clinical

research program that provides state-of-the-art options for wound management.

“The clinical trial is an incredible opportunity for us to impact the lives of our cancer survivors,” Dr. Karni says. “In many cases the cure we provide causes new disease. Cancer survivorship research – looking beyond the cure to what happens afterwards – is a relatively new and exciting area of focus. Through this feasibility study we want to visualize how lymphatics work during metastasis, treatment and recovery to develop an understanding of how lymphatics respond to the cancer itself and the treatment.”

Near-infrared light propagates through several centimeters of tissue. When fluorescent dye is injected, researchers can see the lymph vessel segments pulse in real time as they pump lymph through the body.

The researchers are currently recruiting patients, who will be imaged in Dr. Karni’s office using the technology developed in Dr. Sevick’s lab. A near-infrared fluorescence snapshot will be taken before the start of treatment, after surgery, after radiation therapy and for a year following treatment of each subject.

“We’d like to discover why half of patients treated for head and neck cancer get lymphedema and others don’t,” Dr. Sevick says. “This study has implications for other types of cancer as well. It’s an incredible

opportunity for us to impact the lives of our cancer survivors. The incidence of head and neck cancer is increasing because of human papillomavirus. We’re seeing younger and younger people with the disease, and lost productivity due to disease has a significant economic impact. We’re working to mitigate survivorship disease.”

The NIR fluorescence imaging system is located in Dr. Karni’s office. “We expect to get a treasure trove of data about how lymphatic pathways reorient around the surgical and radiation site,” he says. “If this works as well as we think it will, we’ll be better able to stage head and neck cancer,” Dr. Sevick says. “If we can ultimately identify the lymph nodes that are cancer positive, remove them and leave the others, we may become more efficient at treatment and reduce the risk of lymphedema.”

Editors Note: Ronald J. Karni, MD, serves as Assistant Professor in the Department of Otorhinolaryngology–Head & Neck Surgery at UT Houston. He obtained his medical degree at Baylor College of Medicine and residency training at Washington University in St. Louis School of Medicine. Before joining the Department of Otorhinolaryngology–Head & Neck Surgery at UT Houston, Dr. Karni pursued additional training in neck ultrasonography and transnasal esophagoscopy. Dr. Karni is board certified by the American Board of Otolaryngology–Head & Neck Surgery.

HEAD AND NECK CANCER NEWS

Study examines chronic inflammation in oral cavity and HPV status of head and neck cancers

CHICAGO – Among patients with head and neck squamous cell carcinomas, a history of chronic inflammation in the mouth (periodontitis, i.e. gum disease) may be associated with an increased risk of tumors positive for human papillomavirus (HPV), according to a report published Online First by *Archives of Otolaryngology–Head & Neck Surgery*, a JAMA Network publication.

The National Cancer Institute has reported a steady increase in the prevalence of oropharyngeal cancers in the United States since 1973, despite a significant decline in tobacco use since 1965, according to background information in the study. Similar trends have been recognized worldwide, and the authors note that the increase has mainly been attributed to oral HPV infection.

Mine Tezal, D.D.S., Ph.D., of the

University at Buffalo, and colleagues evaluated data from 124 patients diagnosed with primary squamous cell carcinoma (SCC) of the oral cavity, oropharynx, and larynx between 1999 and 2007 for whom tissue samples and dental records were available.

Of the 124 primary cases of head and neck squamous cell carcinoma, 31 (25 percent) were located in the oral cavity, 49 (39.5 percent) in the oropharynx and 44 (35.5 percent) in the larynx. Fifty (40.3 percent) of the 124 tumor samples were positive for HPV-16 DNA. The authors found that a higher percentage of oropharyngeal cancers were HPV-positive (65.3 percent) compared with oral cavity (29 percent) and laryngeal (20.5 percent) cancers.

Periodontitis history was assessed by alveolar bone loss (ABL) in millimeters

from available dental records. Patients with HPV-positive tumors had significantly higher ABL compared with patients with HPV-negative tumors. Each millimeter of ABL was associated with an increased odds of HPV-positive tumor status 2.6 times after adjustment for other factors. The strength of this association was greater among patients with oropharyngeal SCC compared with those with oral cavity SCC and laryngeal SCC. “Periodontitis is easy to detect and may represent a clinical high-risk profile for oral HPV infection,” the authors conclude. “Prevention or treatment of sources of inflammation in the oral cavity may be a simple yet effective way to reduce the acquisition and persistence of oral HPV infection.”

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CHAPTER NEWS

Two local couples dealing with cancer have found guidance and friendship through a support group they say has been an integral part of the healing process.



Recently, our Ocala, FL SPOHNC Chapter and some of its members were featured in the Ocala Star-Banner. The newspaper interviewed 4 attendees (2 couples) of Amy Roberts group. Terry and Dianne Clendenin and Jerry and Shirley Wolfe shared the stories of their diagnosis and treatment, and talked about the support they found within their SPOHNC Chapter support group.

‘There is Life After Cancer’

Terry Clendenin was diagnosed in November 2007 with oral cancer that spread from his lymph nodes. His wife, Dianne Clendenin, is cancer free. Jerry and Shirley Wolfe both had throat cancer. The couples are part of a SPOHNC Chapter support group for people with oral, head and neck cancer that is led by social worker Amy Roberts of the Robert Boissoneault Oncology Institute.

“We shed a few tears when we first got the diagnosis. Now, in the group, we see not everyone has the same after effects. You really begin to care about your fellow group members,” Terry Clendenin said. “The SPOHNC group has been really helpful, especially with the exchange of ideas like the effect of radiation on one’s dental health,” added Jerry Wolfe.

Shirley Wolfe said she and her husband encourage others going through cancer to

consider a support group such as the one they have been attending. “The sharing of ideas and what has worked and didn’t work has been a great help” she said. “There is life after cancer,” Jerry Wolfe added.

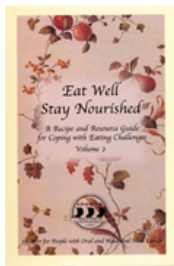
Terry Clendenin praised Roberts, who has worked with cancer patients for more than 10 years, as a “caring person who even came to the hospital to support us.” “Terry and Dianne are mentors in our group,” Roberts said.

This wonderful story shares the importance of support for oral, head and neck cancer patients, survivors and caregivers. These two couples found just what they needed at the Ocala, FL SPOHNC Chapter support group meeting.

Go to www.spohnc.org to find out where your local SPOHNC Chapter support group meets. To start a new SPOHNC Chapter, contact us at 1-800-377-0928.

COOKBOOK NEWS!!

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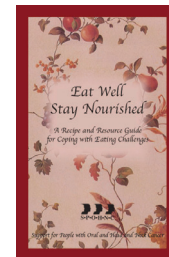


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A TIME FOR SHARING...Time is Hope™ - A Journey of Survival

My wife Esther and I looked forward to our future as empty nesters with bitter-sweet perspective. Our son, RJ, had graduated from high school in May of 2006. Soon after, we made arrangements for moving him to Statesboro, GA. Our daughter, Justine, a Junior at Georgia Southern University, taking summer courses, thrived there as a student. As a family over the years,



we frequently moved around the country for my work. Justine and RJ now took the beginning steps of finding their own paths in

life. Hindsight tells you that although days seem long, the years fly by quickly. We knew the day was coming when we'd have the house to ourselves and we couldn't reconcile the excitement and the sadness at the thought of both Justine and RJ being away. As parents, we were thrilled that they had accomplished so much and were growing up to be successful adults.

We all live our lives on some sort of a schedule, whether it be marked on a calendar for day to day activities or as lifetime milestones such as births, graduations and marriage. We like to pencil in things we'd like to do sometime and ink others in that we anticipate with great excitement and still others that we do because it's that time of the year!

June 2006 marked the time for my annual visit with my cardiologist. I felt good, I never smoked, didn't drink. I had lost some weight because I had been walking two to three miles, five days a week, in addition to strength training, three times a week. As I approached the age of 50, I wanted to continue a healthy lifestyle to keep my family risk of diabetes and heart disease as low as I possibly could. The visit came and went, the full blood workup was great and well within normal ranges. The doctor commented that if I kept this up, I should live a long, healthy life.

He asked if I had any other health related issues to discuss with him. I

described how previous visits to an ENT and Pulmonologist led to treatment with a CPAP (Continuous Positive Airway Pressure) machine for snoring which I had never done before. Constant sinus infections affected my hearing and it kept getting worse. He recommended a different ENT, but said it could take a while to get an appointment with him. I called and they just had a cancellation, so I got an appointment right away.

Because I had been having sinus infections, I thought that this hearing loss was a complication from them. Neither Esther nor I worried about this because as parents, our children had ear infections secondary to colds many times. For most of us, ear infections prove to be a temporary inconvenience. The Physician's Assistant, Ryan, reviewed my medical history and confirmed a significant hearing loss and ordered a CAT scan of my sinuses and an immediate follow up appointment with Dr. Parks.

I quickly discovered myself that Dr. Parks deserves his great reputation. He gives off a positive energy that is contagious to those around him, while taking time with me to get a clear picture of my personal situation. He told me that he wanted to look inside my head with a camera and see what was going on for himself. With the results from the previous week's CAT scan as a guide for where to look, the long flexible probe, with a camera at the tip, was snaked through my nose and up my head and down toward my vocal box. The camera snapped a plethora of photos for documentation.

As soon as the camera went in and up, I sensed it was not good. Dr. Parks' eyes seemed to grow larger and more intense as the staff shuffled in and out, whispering. The camera finished the job at hand and was finally removed and put away. The pictures revealed something that was not normal and needed to be biopsied for a definitive diagnosis. He was concerned with what appeared to be a rapidly expanding mass in my nasopharynx; a difference in size from when the CAT scan had been performed just last week. His exact words were, "This cannot wait and we need to take immediate action. I'm checking on the availability of an operating room so that I can biopsy the

mass. At the same time, I'd like to insert tubes to relieve the fluid pressure that is building up behind your ear drums."

Dr. Parks scheduled the surgery for 7am the next morning, postponing his own vacation! Thursday morning, July 20th, an operating room was available. Dr. Parks reorganized his schedule to accommodate me; his concern and desire to help me still overwhelms me. We needed to move quickly as this foreign mass in my head now commanded an ominous presence. Appointments, tests, words we never heard uttered before, spelled phonetically by us, would soon become part of our everyday vernacular.

We arrived for the biopsy and met with Dr. Parks and the Anesthesiologist. I woke up in recovery and the pressure in my head felt dramatically different; I heard better than I had in weeks! Esther tried to grasp what Dr. Parks told her by asking him repeatedly, "Are you sure it is cancer and not just a benign mass?" Very patiently he painted the picture for both of us that this biopsy's purpose of revealing the type of cells and other information will help determine the best course of treatment with our oncologist, Dr. Debra Miller. He also promised to be with me every step of this battle.

The days dragged on; I wanted to start fighting this with treatment sooner rather than later. My appointment with Dr. Miller gave us more details and a Pet Scan. It was July 24, 2006 when we walked in, sat down and heard the formal diagnosis: Stage 4 nasopharyngeal squamous cell carcinoma (non-HPV). It had spread to the lymph nodes in my neck and chest and it started to eat away at the clivus bone. Where was this clivus bone in my head with its "boney erosion?" Erosion evokes scenes of a shrinking beach front rather than an unknown location somewhere in my head! Needless to say this was not one of those 'yippee for me' moments.

For me, as doctors talked and Esther was asking questions, everything went into slow motion. I looked at the clock and 'Time' and 'Hope' became one for me. Dr. Osmon and Dr. Miller agreed that my best chance for survival depended on a newly approved treatment from ASCO.

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The treatment course covered 100 days, 11 chemo treatments, three of those lasting 5 days each and 35 radiation treatments. Out of all the treatment programs available for my cancer, this one held the greatest odds for a successful outcome. I would have the most current treatment and the one that gave me the best chances in my fight to stay alive.

Dr. Osmon thoroughly covered diagnosis and treatment details and answered all of our questions. We toured the treatment center at Northwest Georgia Oncology. It was difficult to picture myself seated in one of those chairs, connected to an I-V with chemicals running into my veins. Even with my Stage IV diagnosis, I never felt “bad.” I couldn’t hear, but other than that, I was leading a “normal” life. The doctors were amazed I could walk and exercise like I had been, without any other symptoms. When Dr. Osmon placed his hands on my neck and upper chest, I had this tremendous feeling of relief and comfort come over me. This man is a healer! This confirmed my confidence in him, as well as Dr. Miller, to guide me on my journey of survival.

It was my choice to decide what I wanted to do next and I looked at the Oncologists and simply told them I wanted to fight, attack and get after this cancer. I was prepared to attack and keep attacking. I was not going to be nice in fighting back. My way: do not let the cancer have a minute to breathe. I thought that the more you punish ME, the less chance the cancer could survive. I should have remembered that little saying a mother always shares: “Be careful what you ask for.”

As I began treatment, I realized that as well as taking care of my physical self, I needed to maintain my spirit, too. I wanted to keep a positive outlook so I formed a mental image of little soldiers attacking and cutting apart my cancer. I saw my cancer as being a great stealth fighter. It knew how to hide, move, retreat and hit me when I least expected. I imagined it having a mind of its own. Cancer wanted to wear me out and launch a full attack. I was at war with cancer and would not give it any time to breathe. Cancer was my unwelcomed guest and I wanted to show it quickly to the door. *I never pictured the cancer getting the best of me.*

I noticed that many people referred to cancer as my “illness.” Cancer is a scary

word to most of us. It is easier to refer to it as an illness. What is the first word you think of after you hear the word “cancer?” Then ask yourself what is the first word you think about after you hear the word “illness?” I would guess that some of your word answers for cancer are “death,” “fatal,” “terminal.” The word “illness” might make you think “recover,” “temporarily under the weather” or “it can’t be that bad.” It is natural to substitute illness for cancer. Still, I preferred to refer to my cancer as cancer. I wanted to remember that what I fought was “cancer,” not an “illness.” This semantic reality kept my physical, spiritual, and mental images clear and in focus. It was the best and only way for me to win the war going on inside my body.

I met some of the nicest people during my treatments. One man, in particular, eloquently told me a variety of stories about his life. His tales held my interest and I didn’t mind that he kept retelling them. He caught my undivided attention with a new personal account: He had sustained a brain injury, years ago, which affect his memory. Now, like every other patient here in the treatment area, he was fighting cancer. And despite all that happened to him, he was as nice, friendly, and polite a person that you would ever meet. He possessed a positive attitude, too. He reminded me that we all make choices in how we handle adversity. He set a good example for all of us.

The interactions that I had with others helped to carry me through low and frustrating parts of my 100-day treatment course. I wanted to keep on the schedule of 100 days of treatment; no stopping! I knew that my blood counts could drop and treatment could be delayed, but space did not allow for this on my calendar. *Time*. The desire to stay on schedule remained important but the times I spent in the hospital scared me to the unthinkable thoughts of not surviving the treatment. And then just when I thought I couldn’t get through this journey with I-V’s connected to me in so many places that I needed two I-V poles to hold everything, I started to pray. A few minutes after my plea-filled prayer, one of the night nurse’s came in and talked with me. She told me that her son served on the front lines in the war on terror and her work at the hospital helped relieve the stress of worrying about him,

especially in the middle of the night. This conversation reminded me that everyone has trials, tribulations and concerns. We have a choice in how we deal with life and its twists and turns. That night, this nurse brought back to me how many blessings I had in my life.

Once my treatment ended, I fell into the role of surviving the side effects and living as normal a life as possible. While waiting one day for my appointment in Dr. Parks’ office, I noticed a SPOHNC newsletter and I immediately signed up for membership. I liked finding a resource for Head and Neck Survivors that was tailored to our special needs and concerns. In turn, I share the newsletter and site with others who tell me they are grateful for the information from this organization.

Esther and I discovered that living with cancer has its challenges. We realize that life itself continues to have cycles of highs and lows whether or not cancer is present. Instead of allowing cancer to define and dictate what we do with our lives, we live our lives despite cancer. Yes, it is part of our lives and always will be, but so are so many other events and things. We choose to go on and embrace the joys and tackle the challenges.

I became acquainted with a few individuals from the American Cancer Society. We talked and after summing up my story to them, they asked me to speak to a group to tell of my journey of survival. After giving this inspirational account, I realized that I had found my passion. There were many times during treatment when I simply asked, “Lord, get me through this and I will do everything I can to help others.” I have had the privilege of speaking to numerous groups that have included

c o n g r e s s m e n , governors, lawyers, doctors, pharmacists, farmers, housewives, small business owners, community business leaders and local politicians. I also make myself available for one on one mentoring for other cancer patients and their family members. I have obtained the federal trademark for Time is Hope™ as well as created a website



- www.timeishope.com as a means to reach out to survivors and their families.

I like to end my talks with something that caught my eye in Dr. Miller's office on the days I spent in her waiting room. In fact, without knowing that, friends of ours found a similar framed piece and sent it to me as a gift during my treatment.

What Cancer Cannot Do

Cancer is so Limited

It cannot cripple love

It cannot shatter hope

It cannot corrode faith

It cannot destroy peace

It cannot kill friendship

It cannot suppress memories

It cannot silence courage

It cannot invade the soul

It cannot steal eternal life

It cannot conquer the Spirit

***Author Unknown**

Both Esther and I strive to center our lives with our faith in God and his purpose for us. When we do, it grounds us and gives us the drive and strength to continue, one day at a time. Time is hope, and through our hope we have found more time to continue this journey of life.

*Rick and Esther Bowman
ebeckow@comsouth.net*

***Hope is
faith
holding out
its hand
in the dark.***

~ George Iles

THANKSGIVING & GRATITUDE

As the season of giving thanks is now upon us, gratitude is always a word that comes to mind. Family gatherings, or just quiet time alone makes us pause to reflect upon the past year, and to be grateful for where we are today.

We at SPOHNC are grateful...for those we speak to, and offer help to each day, by phone or by e-mail. We are grateful that we have the opportunity to help you, offer hope and encouragement



and to be there when someone needs us. It is a privilege and an honor to be here – for patients, survivors, caregivers, friends and healthcare professionals.

For all of our SPOHNC volunteers... Chapter Facilitators and Co-Facilitators, National Survivor Volunteer Network volunteers, the members of our Board of Directors and our Medical Advisory Board, those who have authored feature articles and Sharing Stories for our newsletter, our event or meeting speakers and all of those who have been there to help – with a Taste or Awareness event, whether medical professionals, chefs, entertainers, or even students who help us throughout the year - We are grateful.

Gratitude comes in so many forms. It can be a touch, a smile, or a welcome voice on the phone. How can you find gratitude in your day – every day? Where have you felt it, or seen it in action?

Here are some grateful thoughts that have been shared with SPOHNC this year...

From a Survivor...“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!!!!”

~ Dave N.

From a Facilitator...“I have been inspired by the courage of the participants, the generosity they have shown by sharing their stories and wisdom, and the amazing support of each other.”

~ Jayne O.

From the Daughter of a Newly Diagnosed Patient...“I really appreciate SPOHNC, what it does to help those with like diagnosis as well as their friends, family and caregivers.”

~ Sandra V.

From an NSVN Volunteer...“By helping someone else, I help myself too. It always amazes me how good I feel after being able to help.”

~ Rita B.

From a Caregiver/Chapter Co-Facilitator...“We are still trying to figure out why this group is as special and wonderful as it is...After each meeting, Lewis and I get into the car, and we give each other a kiss, and say how lucky we are to be able to do this.”

~ Amy B.

As we look forward to the coming year and give thanks for all that we are, and all that we can become, reflecting upon the words of others can sometimes be helpful and encouraging.

“Gratitude unlocks the fullness of life.

*It turns what we have
into enough, and more.*

*It turns denial into acceptance,
chaos to order, confusion to clarity.*

*It can turn a meal into a feast,
a house into a home,
a stranger into a friend.*

*Gratitude makes sense of our past,
brings peace for today,
and creates*

a vision for tomorrow.”

~ Melody Beattie

With gratitude, SPOHNC offers our best wishes to you, your family and friends, for a blessed Thanksgiving.

HEAD AND NECK CANCER NEWS

Start Swallowing, Eating ASAP in Oral Cancer Therapy

Sep 20, 2013 - Patients with oral cancers had significantly better long-term diet if they received oral feeding and practiced swallowing exercises during radiation therapy, data from a large retrospective cohort showed. In adjusted models, both swallowing goals had independent associations with long-term diet ($P < 0.05$), according to Katherine A. Hutcheson, PhD, of the University of Texas MD Anderson Cancer Center in Houston, and co-authors.

Patients who maintained full oral intake were twice as likely to eat a regular diet during long-term follow-up (OR 2.0, 95% CI 1.0-4.6) and patients adherent to swallowing exercises were four times as likely to return to a regular diet (OR 4.0, 95% C 1.9-6.4), they reported online in *JAMA Otolaryngology Head and Neck Surgery*. Both oral intake and swallowing exercises also were associated with a reduced duration of gastrostomy dependence.

“Proactive swallowing therapy and swallowing exercise adherence should be considered an essential component of modern, multidisciplinary head and neck care,” they added. “Our findings, in concert with those of prior rigorous trials, offer support for early referral to the speech pathologist to begin proactive swallowing therapy before definitive radiation therapy or chemoradiation therapy.”

Modern therapy for pharyngeal and other types of oral cancer focuses on locoregional control and preserving function. As part of their treatment, most patients receive radiation therapy or chemoradiation, which leads to dysphagia in as many as two-thirds of cases, the authors said in their introduction. In severe cases, dysphagia can result in dietary restriction and malnutrition that require long-term, if not life-long, dependence on feeding via gastrostomy.

The advent of modern radiation therapy protocols designed to spare normal tissue has reduced the frequency of long-term dependence on gastrostomy. Still, as many as 12% of patients cannot be weaned off gastrostomy feeding in a short period of time.

Proactive swallowing exercises have been standard treatment for patients with pharyngeal cancer, supported by both observational studies and randomized trials, the authors

continued. However, toxic effects of radiation therapy and chemoradiation make eating difficult, and many patients require gastrostomy tubes and dietary restrictions that include avoidance of solid foods.

Limitations on oral intake lead to disuse of oral musculature and adverse remodeling of aerodigestive tract muscles that exacerbates the effects of radiation-induced edema and fibrosis. “Thus, the central premise of proactive swallowing therapy is ‘use it or lose it’ to mitigate the muscular wasting and remodelling that occurs after even brief intervals of disuse,” the authors noted.

Proactive swallowing exercises aim to reduce prolonged periods of no oral feeding. The benefits of eating and exercise have been reported separately, but data are lacking on the independent effects. Hutcheson and colleagues examined data on almost 500 patients in an attempt to define the independent effects of eating and swallowing.

They reviewed records of 659 patients with oropharyngeal or hypopharyngeal cancer treated with definitive radiation therapy, with or without chemotherapy, from 2002 to 2008. After exclusions, 497 patients remained for the analysis. The primary outcomes were oral feeding status at the end of radiation therapy (or chemoradiation) and self-reported adherence to swallowing exercises.

Most patients had oropharyngeal cancer, and most had nodal involvement ($81\% \geq N2$). Intensity-modulated radiation therapy was used in 91% of cases, and 77% of patients received systemic therapy, which was administered concurrently in 234 of 497 (49%) patients.

The authors reported that 366 of 497 (74%) patients maintained oral intake throughout radiation therapy. The data showed that 131 (26%) patients had no oral intake at the end of radiotherapy or chemoradiation, 167 (34%) had partial oral intake, and 199 (40%) had complete oral intake. Complete oral intake consisted of pureed or liquid diets in 87 patients and solids in 112 patients.

Of 388 (76%) patients who had consultations with a speech pathologist, 286 (58% of the total patient population) reported adherence to swallowing exercises.

Overall, 13% of patients met neither goal of oral intake or adherence to swallowing exercises, 64% met some goals with at least partial oral intake and/or exercise adherence, and 24% of patients continued full oral intake throughout treatment and adherence to swallowing exercises.

After completing treatment, 402 (81%) patients resumed a regular diet. During a median follow-up of 22 months, significantly more patients who maintained full oral feeding or practiced swallowing exercises consumed a regular diet.

- 65% of patients who were NPO and did not practice swallowing exercises
- 77% to 84% of patients who met some of the eating/swallowing goals
- 92% of patients who met eating and swallowing goals

Subgroup analyses showed that full oral feeding led to better outcomes than did partial oral feeding among patients who were adherent to swallowing exercises ($P = 0.02$), and patients who were adherent versus nonadherent to swallowing exercises did better among the subgroup of patients who maintained full oral feeding throughout radiation therapy ($P = 0.02$).

Median duration of gastrostomy dependence was 222 days in patients who were NPO and did not adhere to swallowing exercises, 151 to 157 days in patients who were partly adherent, and 111 days in patients who continued oral intake and remained adherent to the exercises ($P = 0.03$ for trend).

“Long-term swallowing outcomes were best in patients who both maintained full [oral intake] throughout radiation therapy or chemoradiation therapy and reported adherence to swallowing exercises and uniformly worst in those who were [nothing by mouth, NPO] at the end of treatment and nonadherent to the exercise regimen,” Hutcheson and co-authors concluded.

The study was supported by the University of Texas School of Public Health and the Research Institute of Texas. The authors reported no relevant disclosures.

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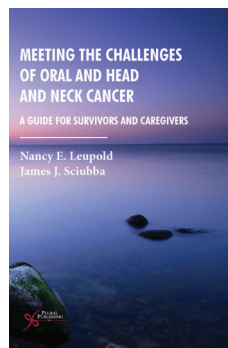
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“Being part of SPOHNC and facilitating our local head and neck cancer support group at Gilda’s Club in Nashville is a great blessing to me. It has been an incredibly humbling, rewarding, and inspiring experience.”

~ Carmin B.



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~ Robbie D.



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