

## Head and Neck Lymphedema: Shedding Light on a Unique Condition

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### Introduction

Many patients who have been treated for head and neck cancer (HNC) are surprised by the swelling under their chin or in their face that fails to resolve even after several weeks of post treatment recovery. They often report that head and neck lymphedema (HNL) was not something they were aware of or expecting when they were diagnosed with head and neck cancer. HNL is a



complication that is generally not conveyed or discussed by their physician. They are referred by their physician (surgeon, radiation oncologist, plastic reconstructive surgeon, medical oncologist, among other physicians), generally unsure of what purpose the appointment will serve. Most patients are unaware that the discomfort they are feeling or the problems they are experiencing eating, talking, seeing, maybe even breathing, are occurring because of an often under-recognized disease known as head and neck lymphedema.

### Definition

Lymphedema is chronic swelling which results from injury to the lymphatic system, the body's vehicle for the transportation of fluid throughout the body. In essence, the damage blocks normal drainage pathways. The impairment can be hereditary, as a result of trauma, or iatrogenic, resulting from medical

intervention. Most people are familiar with the lymphedema that causes swelling of the arm in patients who have been treated for breast cancer, although lymphedema also occurs in patients after treatment for melanoma and genitourinary malignancies. In patients with HNC, lymphedema mostly occurs after surgery or radiation to the head and neck region. Generally, surgery removes lymph nodes that are important for filtering and facilitating fluid movement. Alternatively, radiation impairs fluid transport as a result of damage to lymphatic vessel contractility associated with fibrotic changes that impede the pumping action of the vessels. In some cases, the tumor itself may cause vessel obstruction. Ultimately, lymph fluid builds up in the affected area that results in swelling.



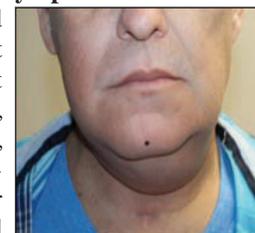
Why is it that HNL is unfamiliar to so many patients? Despite an increased interest in HNL over the past decade, information remains sparse and scientific examination is limited. There are few publications regarding the evaluation and effectiveness of conservative treatments for this disease. Unfortunately, head and neck lymphedema remains under-recognized and therefore, undertreated. Furthermore, the widely held belief that head and neck lymphedema will spontaneously resolve with time further undermines the gravity of the disease and the need for targeted intervention.

### Incidence

According to the American Cancer Society, there were an estimated 1.6 million new cases of cancers diagnosed in 2014, of which 3% occurred in the head and neck region.<sup>1</sup> The incidence of HNL has been reported between 50% and 75% in patients treated for head and neck cancer.<sup>2,3</sup> Therefore, almost 42,000 patients of the approximate 55,000 men and women diagnosed with tumors of the oral cavity, larynx, and pharynx, are at risk to develop lymphedema. Even though head and neck lymphedema is a common complication of HNC treatment, the actual number of people who are affected remains relatively small. Thus, most people have little knowledge of this debilitating disease.

### Effects of Head and Neck Lymphedema

Lymphedema that affects the head and neck region will result in significant cosmetic and functional sequelae that may include problems with articulation, mastication, swallowing, drooling, airway obstruction, vision and poor self-image.<sup>4</sup> Swelling, or edema, can appear in any part of the head and neck, and



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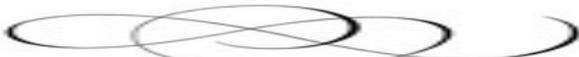
**Chris Leonardis**

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severity will vary. Note the lymphedema under the chin of a patient with HNL who has been treated with radiation shown in Figure 1. Patients often complain of discomfort and embarrassment. Although the majority of patients present with externally visible swelling, sometimes lymphedema can affect internal structures including the tongue, pharynx (throat), and, larynx (voicebox) that will also impact eating, speaking, and sometimes breathing. Figure 2 shows an X-ray illustrating lymphedema in front of the spine that is narrowing the throat and causing swallowing problems.



Patients often ask, “Why am I seeing a speech-language pathologist?” At MD Anderson Cancer Center, patients with head and neck lymphedema are evaluated and treated by certified speech pathologists who are also certified lymphedema therapists (CLTs) who have special training in HNL. The benefit is that patients receive targeted treatment for their head and neck lymphedema along with focused exercise protocols designed to maximize speech and swallowing. In all cases, patients are relieved to know the cause, and excited to learn that their HNL can be successfully managed. Patients with lymphedema that affects the extremities or other parts of the body continue to be managed by our physical and occupational therapy colleagues.

**Complete Decongestive Therapy (CDT)**

Complete decongestive therapy (CDT) remains the gold standard for lymphedema treatment.<sup>5</sup> This therapy has 4 components: manual lymph drainage (MLD), tissue compression with bandaging and/or garments, exercise, and skin care. Typically, complete decongestive therapy is divided into 2 phases. The intensive phase consists of daily treatment that is provided on an inpatient or outpatient basis provided by a certified lymphedema therapist (CLT) . During this treatment phase the therapist provides the therapy while teaching the patient and family to perform the CDT regimen independently at home. Ideally, the intensive phase takes place over the course of several weeks. During this time, it is not uncommon to see rapid and significant reduction in the amount of swelling.

The second phase of **complete decongestive therapy** is the maintenance phase and relies on the independent application of the treatment plan by the patient at home. A recent study published by clinical investigators at MD Anderson Cancer Center of over 1,200 patients treated for HNL, revealed that 60% of patients showed improvement whether they were fully or partially adherent to their treatment program regardless of treatment setting, (CLT administered or home program) and the severity (disease stage)



of their HNL.<sup>4</sup> Figure 3 shows the pre- and post-treatment photos of a patient who had a significant response after independently performing a self-administered home program of CDT. The take home message -- when HNL is properly evaluated and treated, patients improve! This is a very important and encouraging finding for patients without local access to an experienced

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lymphedema therapist, but who are able to implement a home program themselves or with a family member.

### Presentation

Lymphedema that affects the region of the head and neck is quite different from lymphedema that affects the arms and legs. Often, HNL occurs in an area that has previously been irradiated or treated surgically. In contrast, extremities affected by lymphedema, particularly in the arms of treated breast cancer patients, generally have not been irradiated. Radiation causes tissue damage that may interfere with manual lymph drainage and compression. In patients with HNL, alternative drainage pathways that avoid the irradiated area are often unavailable and therefore, treatment, MLD and compression, must be performed within the affected area. Patients with extremity lymphedema tell us that their swelling is worse at the end of the day because the limbs have been in a downward position and the effects of gravity have allowed fluid to pool in the appendage. They report less swelling when they wake up in the morning as the body and limbs have been in a horizontal position that impedes fluid build-up. In contrast, patients with HNL experience the worst amount of swelling when they lay down, generally waking with marked swelling in the face and neck. Upright positioning throughout the day for patients with head and neck lymphedema facilitates better fluid transport because gravity moves the fluid away from the head and the neck.

### Evaluation and Treatment

The significance of differences between HNL and extremity lymphedema is important because of the impact to both evaluation and treatment. Patients with HNL require different evaluation approaches because current methods of assessment for extremity lymphedema fail to capture the unique characteristics of HNL that differ from those seen in patients with swollen arms and legs. The unique features of HNL spearheaded the clinical research team from MD Anderson

Cancer Center to develop a new rating scale specifically designed to evaluate and grade the severity of HNL in affected patients.<sup>6</sup>

Treatment approaches also differ. For example, circumferential bandaging to the cervical neck region is not practical for the patient with HNL, as the risk for damage and injury to vital structures such as the trachea, carotid arteries, and jugular veins is significant. In addition, applying circular pressure around the neck simply pushes the fluid upward into the face. Therefore, compression bandaging is useful in patients with extremity lymphedema but may be contraindicated for patients with HNL. For some patients with HNL, compression garments and custom cut foam pads are preferred.

The focus of treatment for head and neck lymphedema remains manual lymph drainage and compression in contrast to the exercise and skin care that many patients with extremity lymphedema require. Although patients with HNL are encouraged to perform targeted exercises for swallowing while wearing compression garments, the efficacy of this approach has not been substantiated. Whether there is a benefit for HNL patients to exercise while wearing compression garments requires further investigation. However, the advantage of exercise with compression has been widely demonstrated for patients with extremity lymphedema.<sup>7</sup> Although skin care is always important for all patients regardless of the site of edema, significant skin ailments such as papillomatosis (a benign lesion of the skin), and recurrent infection are generally not complications of HNL. Hence, focused skin care is not a critical priority for most patients with HNL.

Manual lymph drainage that is performed properly remains key to the successful treatment of HNL. The method is similar for both patients with HNL and extremity lymphedema. Although the usefulness of MLD continues to be debated in some professional circles, experienced lymphedema therapists uphold the value and contribution that MLD provides to successful lymphedema management. Figure 4 demonstrates treatment with MLD. MLD is a very light massage that directs lymph fluid

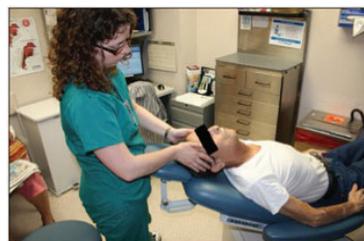
from the affected area to a part of the body with healthy, functioning lymph nodes. For most patients with HNL, this means moving lymph from the head and neck region to the lymph nodes in the armpits. Although the technique for **Complete Decongestive Therapy**, specifically, MLD, is basically similar, there may be some variation among clinicians of varying backgrounds in its application. Some clinicians favor skin stretching<sup>8</sup> while others prefer a brushing or rhythmic tapping of the fingertips<sup>9</sup> along the lymphedematous area. In most cases, the method of MLD that is used remains the preferred technique of the treating lymphedema therapist based on his or her training.

### Future Directions

Although CDT effectively reduces lymphedema in most patients, there are some patients whose HNL continues to be refractory to management. New procedures for evaluation and treatment are emerging for patients who are unresponsive to current methods of practice. Near-infrared imaging of lymph vessels that are close to the surface of the skin offers a new avenue for clinicians to find functioning lymphatic vessels that are invisible to the naked eye. In addition, surgeons are learning novel procedures that allow them the ability to perform operations on lymphatic vessels no larger than a fraction of a millimeter in diameter. These “cutting edge” alternatives, among others, offer new hope for patients who have exhausted all options of conservative treatment.

### Conclusion

Experience shows that head and neck lymphedema results in significant cosmetic problems but more important, HNL can result in debilitating functional deficits that interfere with many of the activities that we take for granted—the ability to talk with friends and family, enjoy a meal at a restaurant, behold a beautiful landscape, or marvel at a child’s first step. HNL can be successfully managed with excellent opportunity for patients to live unencumbered by their disease; unfortunately, there is no cure at the present time for



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HNL. Head and neck lymphedema remains distinctly different from lymphedema in other sites and therefore requires specialized treatment from experienced lymphedema therapists who are well-trained and familiar with patients whose edema affects the head and neck. Many patients, once successfully treated, will not need life-time therapy. Still, HNL remains an extremely under-recognized and poorly managed complication of head and neck cancer. Future investigations will improve our knowledge of the disease, distinguish important aspects associated with long-term response, help minimize lymphatic damage, and establish new methods of treatment for patients with this condition. It is essential that while we are working on the cure, we optimize the quality of life for patients who must live with head and neck lymphedema.

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*at MD Anderson is recognized as the premier program for functional rehabilitation of oncology patients.*

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Another state has joined SPOHNC! The **SPOHNC Rhode Island** Chapter support group meets at The Neighbourhood Guild in Peace Dale, Rhode Island. Chapter Facilitator, Donna Averill, is a survivor, and has been an active community volunteer for many years. Her experience and assistance with community organizations, in addition to her passion for survivorship, will undoubtedly be an asset as she takes on her role as Chapter Facilitator. It's great to welcome a new state to the SPOHNC family!

Michigan welcomes a third SPOHNC Chapter, as we tip our hats to **SPOHNC - Ann Arbor**. The group will meet at Mercy Hospital Cancer Center, and will be facilitated by Social Worker, Mary Ellen McBride. Mary Ellen has 15 years of experience as a medical social worker in the field of radiation oncology, where she has assisted countless patients and their families as they traveled their cancer journey. SPOHNC is grateful for her supportive and caring hand as she guides her group attendees along the way.

**SPOHNC** would like to welcome our new group in **Savannah, Georgia**. The group will meet at Curtis and Elizabeth Anderson Cancer Institute on the 3rd Wednesday of the month from 2 – 3 pm. Chapter Facilitator Jennifer Currin-McCullough will utilize her 10+ years of group facilitating experience, and her 19 years of experience as an oncology social worker, to provide the support needed by our newest Georgia group. She will be assisted by Chapter Co-Facilitator Suzy B. Harmon. Welcome Savannah to the ever-growing family of SPOHNC Chapters!

## TIME FOR SHARING...Oh No! This Can't Be

What a beautiful day! No wind, perfect for tennis. April 5, 1999, Chuck and I had gotten up at 6AM for our morning walk around the golf course. I'd just thrown on a sweat suit and barely looked in the mirror as I combed my hair. Now we were back, had finished breakfast and I was about to take a shower when I saw it, a lump on my neck! Instantly feeling petrified, I called my doctor's office. My doctor wouldn't be in this week but I was given an appointment to see his assistant.

After examining my neck and asking questions about other possible symptoms the P. A. said, "It's probably just a virus but I'll give you a prescription for an antibiotic you need to take for ten days. If that doesn't take care of it, then I'll send you to Santa Barbara to see an Ear, Nose and Throat specialist." I felt a little bit calmed but spent the next ten days looking in the mirror trying to determine if the lump was getting smaller or larger. It definitely wasn't disappearing.

Two weeks later I saw my doctor and he made an appointment for me in Santa Barbara with an Ear, Nose and Throat specialist. When I saw the ENT a few days later he detected a very strong pulse in the lump so was hesitant to stick a needle in it for a biopsy in case the vascular system was involved. He sent me to Cottage Hospital for an ultrasound, which showed the lump on top of the carotid artery and showed that the vascular system was not involved. Three days later a needle biopsy was done and I received a call at home that evening telling me the lump was not malignant. Wow! What a relief! My tension started to melt away. But, wait a minute; the doctor was still talking and he was telling me he wanted me to come back in for a CT scan of my neck. The CT scan was done and four days later the ENT removed the lymph node involved plus six others.

The doctor was standing by my bed when I came to after the surgery. He said he was sorry to have to tell me, but the pathology report indicated a malignancy. Chuck was there with me and we immediately decided there were no options – I would win! Whatever it took, whatever I had to do, it was okay. Only 68, I had a lot of living to do, my list was still long! My daughter was pregnant with my second grandchild so I had to be there!

The doctor seemed reluctant to accept the diagnosis, "Transitional cell cancer, T 1, N 1, Stage 3." He asked my permission to send the pathology samples to the Armed Forces Institute of Pathology in Washington, D. C. for their opinion. His reason was that transitional cell cancer almost always starts in the kidneys/bladder/urinary track area. I'd already had a CT scan of those areas and a "scope" performed by a urologist and nothing suspicious was found.

I've learned that treating cancer without knowing where the primary tumor started is problematic. The clock was ticking. Seven weeks had passed since I'd found the lump and it was clear the doctors were worried. Many more examinations and tests were scheduled. I saw my doctor for an examination of my breasts; he explained that cancer cells have "estrogen receptors" so it is possible this is breast cancer but he didn't think so. Two days later I had a mammogram and a bladder scope, saw a gynecologist and a surgeon. All examinations and tests were negative; nothing suspicious was found.

More tests were ordered and given priority appointments. I had a full body PET scan, an MRI of my head, a CT scan of my chest and donated blood for multiple tests. On June 11<sup>th</sup> the pathology report came back from Washington, D. C. Diagnosis: metastatic carcinoma with features suggestive of "squamous cell" cancer.

My niece in Riverside, CA had worked for the American Cancer Society for many years. Her office was in Loma Linda Medical Center and her primary work was with cancer doctors throughout the country. She had been following my saga and offering advice as to what I should ask the doctors, etc. She arranged priority appointments for me at her hospital with a general medical oncologist and a top Ear, Nose and Throat doctor. Chuck and I drove to Riverside to my sister's house carrying

all of my scans, reports and a synopsis of my case.

First I saw the oncologist. He reviewed my pathology reports and synopsis and immediately said "This is a head and neck cancer."

Next I saw the ENT surgeon. He examined me with the laryngoscope and found what he believed was the primary tumor. He saw an ulcerated place in a crevice just above the epiglottis on the right side. Pointing to a spot on the illuminated scan, he said, "Here, I'll show you. The tip-off is this asymmetrical area." He recommended I have "blind" biopsies of the nasopharyngeal area and the larynx.

My ENT Surgeon suggested that I seek treatment at a facility in Santa Barbara, where I would receive excellent care, and would be comfortable because I'd be close to home. He knew that was important to me. A complete report was put together for the Santa Barbara doctors and a phone consultation took place.

My ENT did the biopsies; he told us the preliminary results were positive and that he'd removed a "pea-size" tumor at the base of the tongue on the right side. After consulting with another physician, the oncologist and head of The Cancer Foundation in Santa Barbara said that a treatment plan was in the works. I would have radiation treatment and, possibly, chemotherapy as well. Clinical trials were indicating that there may be benefit in having both. Prior to getting measured for the mask that would hold my head and neck absolutely still for the radiation treatments, I was told that there was "no established benefit" for chemotherapy so I would only be getting radiation.

July 8, 1999 – three months and three days after I first saw that lump - my first radiation treatment – I'm feeling relieved that treatment has finally started! I'll have two treatments a day, five days a week for five or six weeks. We decided to stay in a nice motel a block from the treatment center and only go home on weekends.

August 19, 1999. Last treatment day! Hooray! It's over! I'm finished with cancer!

Epilogue: I feel so fortunate that I survived and have not had major problems since. My throat was sore and swollen

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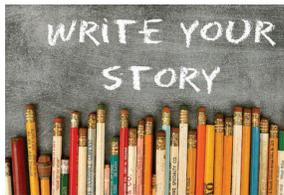
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making it impossible to eat for a few weeks after treatment ended. My saliva glands had been destroyed. I lived on liquid nutritional nourishment. Finally, after a month, I began eating soup and gradually added other things. Sixteen years later I still need all of my food very moist but with good texture and wash everything down with water. Immediately after treatment ended, I almost constantly sipped from a bottle of water. I couldn't even talk without sipping; as my throat would get so dry I couldn't get the words out. My throat would get very painful if I didn't have water readily available, even during the night. After about four years, I developed a very sore spot under my right jaw. Dreading the worst, I went to see my cancer doctor and was relieved to learn it was a saliva gland regenerating. "Most unusual this long after treatment; usually, if they're going to come back they come back within the first year," according to the doctor who saw me. Just a small amount of saliva has helped and I can eat almost everything I could eat before cancer. Nothing tastes the same as it did before but I have grown used to the new tastes.

Six years post treatment, my doctor dismissed me as his patient. He said after six years of checkups, monthly, quarterly, every six months, then annually, I am doing great and really don't need to see him anymore. As far as he's concerned, I'm cured!

~ Betty Moorhead  
bsm98467@comcast.net

### WOULD YOU LIKE TO SHARE YOUR JOURNEY WITH OUR READERS?



SPOHNC is currently seeking Sharing Stories for upcoming issues of News from SPOHNC. Why not inspire others with your courage, determination and the faith to go forward?  
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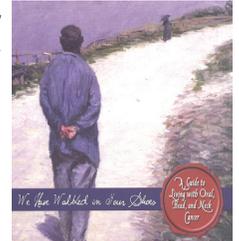
### Great News!!

## We Have Walked In Your Shoes - Second Edition Is Here!

The long-anticipated and **updated** version of *We Have Walked in Your Shoes: A Guide to Living with Oral, Head and Neck Cancer – Second Edition* is now available!

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### From SPOHNC's Kansas City, KS Chapter Facilitator

I am the Facilitator of the Kansas City Chapter at the Kansas University Cancer Center. For the last five years my predecessor Mary Moody and I, along with our Chapter, have been hosting a Tasting Event at our facility to help raise awareness of oral, head and neck cancer, while creating an evening of camaraderie amongst our patients, their families and those involved in their treatments to share the friendships and support we have developed along everyone's journey with this disease. It is an event where survivors can mingle with others socially and enjoy a meal together and some fun too!

It's been a wonderful evening shared with people from all walks of life, with their physicians speaking about the many advances the medical field has been able to develop to treat this disease. As we all know - Head and Neck Cancer is a rare disease that everyone should know about.

The Kansas City Chapter Tasting Event is a group effort with attendees, their families and our healthcare team at the facility. We engage chefs from the area to donate a dish that supports the special needs of head and neck cancer patients. Our chefs are more than happy to contribute and make a difference in our community. Volunteers have stepped up to help create this event for everyone to share in their survivorship and to promote awareness. We never imagined how our Tasting Event

would grow and become an annual occasion that everyone looks forward to.

So many of you might hesitate to even undertake such a task, and I know that SPOHNC headquarters understands your apprehension and concern. Every month each chapter meets to support another patient and another caregiver. Maybe with that same support, each attendee would be willing to "go the extra mile" and work together to do an event similar to Kansas City's, or perhaps a completely different event? No event is too small or too grand.

SPOHNC's guidelines are available by e-mailing [info@spoHNC.org](mailto:info@spoHNC.org). All you have to do is fill out the Third Party Application when you decide what kind of event you'll be hosting, whether it be a Tasting Event, Move to Music event, Bake Sale, Oral Cancer Screening, Health Fair, an Awareness Kiosk in a mall, Motorcycle Run, Dog and People Walk etc.

I hope you will join me, and the Kansas City Chapter, by promoting awareness in your community in your own unique way. It's been a very rewarding experience to give back to the community that helped us form this wonderful support network that we all share.

Sincerely,

Dorothy Austin, RN, OCN  
Chapter Facilitator, SPOHNC Kansas City, KS

Visit the SPOHNC website at [www.spoHNC.org](http://www.spoHNC.org)

## HEAD AND NECK CANCER NEWS

### Coupling head and neck cancer screening, lung cancer scans could improve survival

January 9, 2015 - University of Pittsburgh Schools of the Health Sciences –

Adding head and neck cancer screenings to recommended lung cancer screenings would likely improve early detection and survival, according to a multidisciplinary team led by scientists affiliated with the University of Pittsburgh Cancer Institute (UPCI), a partner with UPMC CancerCenter.

In an analysis published in the journal *Cancer* and funded by the National Institutes of Health (NIH), the team provides a rationale for a national clinical trial to assess the effectiveness of adding examination of the head and neck to lung cancer screening programs. People most at risk for lung cancer are also those most at risk for head and neck cancer.

“When caught early, the five-year survival rate for head and neck cancer is over 83 percent,” said senior author Brenda Diergaarde, Ph.D., assistant professor of epidemiology at Pitt’s Graduate School of Public Health and member of the UPCI. “However, the majority of cases are diagnosed later when survival rates generally shrink below 50 percent. There is a strong need to develop strategies that will result in identification of the cancer when it

can still be successfully treated.”

Head and neck cancer is the world’s sixth-most common type of cancer. Worldwide every year, 600,000 people are diagnosed with it and about 350,000 die. Tobacco use and alcohol consumption are the major risk factors for developing the cancer.

The early symptoms are typically a lump or sore in the mouth or throat, trouble swallowing or a voice change, which are often brushed off as a cold or something that will heal. Treatment, particularly in later stages, can be disfiguring and can change the way a person talks or eats. Dr. Diergaarde and her team analyzed the records of 3,587 people enrolled in the Pittsburgh Lung Screening Study (PLuSS), which consists of current and ex-smokers aged 50 and older, to see if they had a higher chance of developing head and neck cancer.

In the general U.S. population, fewer than 43 per 100,000 people would be expected to develop head and neck cancer annually among those 50 and older. Among the PLuSS participants, the rate was 71.4 cases annually per 100,000 people.

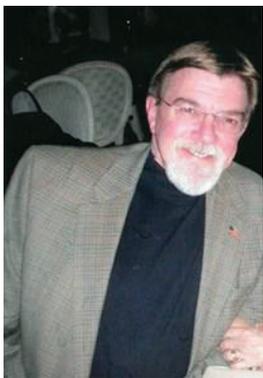
Recently, the U.S. Preventive Services Task Force, as well as the American Cancer

Society and several other organizations, recommended annual screening for lung cancer with low-dose computed tomography in people 55 to 74 years old with a smoking history averaging at least a pack a day for a total of 30 years. The recommendation came after a national clinical trial showed that such screening reduces lung cancer mortality.

“Head and neck cancer is relatively rare, and screening the general population would be impractical,” said co-author David O. Wilson, M.D., M.P.H., associate director of UPMC’s Lung Cancer Center. “However, the patients at risk for lung cancer whom we would refer for the newly recommended annual screening are the same patients that our study shows also likely would benefit from regular head and neck cancer screenings. If such screening reduces mortality in these at-risk patients, that would be a convenient way to increase early detection and save lives.”

Dr. Diergaarde’s team is collaborating with otolaryngologists to design a national trial that would determine if regular head and neck cancer screenings for people referred for lung cancer screenings would indeed reduce mortality.

## IN MEMORIAM



It is with a very, very heavy heart that we share the news of the passing of Larry “Brad” Pate. Brad was one of only 6 individuals who attended the first meeting of the Dallas/Baylor (Texas) SPOHNC meeting back in 2001. Group facilitator, Dan Stack, shared these thoughts of Brad with SPOHNC, recently... “When a topic came up that no one in the group knew much about, Brad always did the research and came back to the next meeting with his findings. We will truly miss him and his dry sense of humor.”

Brad was an active volunteer for SPOHNC’s National Survivor Volunteer Network since December of 2004. He generously gave of his time, listening to the concerns and questions of newly diagnosed patients and their caregivers, and helping them through their journey and beyond. He was a kind, generous and warm-hearted gentleman, and we will miss him. SPOHNC will keep Brad’s family in our thoughts and prayers.



*“What we have once enjoyed we can never lose. All that we love deeply becomes a part of us.”*

~ Helen Keller

*“Life is precious,  
love is all  
that really matters, and  
who we are in the end  
and how we’ve touched  
the lives of others  
is the legacy  
we leave behind”*

~ Erika Whitmore Godwin



## SURVIVOR NEWS AND CONGRATULATIONS!



*Left to right - Bill O'Rourke & Ed Martin were married January 24, 2015.*

In 2004, Ed Martin was diagnosed with adenocarcinoma of the nasal cavity and

maxillary from a routine dental examine. Ed opted for aggressive radiation and chemotherapy, which kept the tumor from growing for a decade. When the tumor grew last year, he tried the newly developed Cyberknife proton therapy at Boston's Beth Israel Hospital.

In lieu of gifts at their wedding, they requested their guests make donations to SPOHNC. Bill explained "When Ed suggested SPOHNC, it just seemed like the right thing to do." Thank you Bill & Ed!

\*\*\*\*\*



## SHARE YOUR GOOD NEWS!!



*Do you enjoy reading about the happy news in the lives of survivors like you?*

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Send your stories and photos to [info@spohnc.org](mailto:info@spohnc.org).

## Easy Shepherds Pie

*(from Eat Well Stay Nourished A Recipe and Resource Guide For Coping With Eating Challenges Volume 2)*

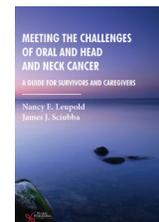
- 1 lb. leftover minced lamb or minced, cooked beef
- 1 onion, finely chopped
- 4 Tbsp. butter
- ½ c. beef broth
- 1 tsp. Worcestershire sauce
- Salt & pepper to taste
- 4 c. mashed potatoes
- ½ c. grated Cheddar cheese



Melt butter in saucepan and sauté beef or lamb with chopped onions. Do not drain. Add beef broth and Worcestershire sauce to the meat and onions, stirring until juices are thoroughly mixed and meat is heated. In an 8 x 8 inch baking dish, spread the beef and onions. Spread the mashed potatoes evenly over meat. Distribute cheese on top of potatoes. Bake at 400 degrees until cheese is melted and pie is bubbling. Serves 6.

~ Hannah Swenson, New York

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## HEAD AND NECK CANCERNEWS

### NIH-funded study uncovers range of molecular alterations in head and neck cancers, new potential drug targets; TCGA tumor genome sequencing analyses offer new insights into the effects of HPV and smoking

January 28, 2015 - Investigators with The Cancer Genome Atlas (TCGA) Research Network have discovered genomic differences – with potentially important clinical implications – in head and neck cancers caused by infection with the human papillomavirus (HPV). HPV is the most common sexually transmitted virus in the United States, and the number of HPV-related head and neck cancers has been growing. Almost every sexually active person will acquire HPV at some point in their lives, according to the Centers for Disease Control and Prevention.

The researchers also uncovered new smoking-related cancer subtypes and potential new drug targets, and found numerous genomic similarities with other cancer types. Taken together, this study's findings may provide more detailed explanations of how HPV infection and smoking play roles in head and neck cancer risk and disease development, and offer potential novel diagnostic and treatment directions.

The study is the most comprehensive examination to date of genomic alterations in head and neck cancers. The results were published online Jan. 28, 2015 in the journal *Nature*. TCGA is jointly supported and managed by the National Cancer Institute (NCI) and the National Human Genome Research Institute (NHGRI), both parts of the National Institutes of Health.

The U.S. Food and Drug Administration-approved HPV vaccines should be able to prevent the cancers caused by HPV infection in head and neck cancers and elsewhere, including anal cancer, whose incidence has also been increasing. However, these vaccines work by preventing new infections, and the long interval between infection and cancer development make it important to understand the molecular changes that bring about these HPV-positive head and neck cancers – as well as those that lead to the HPV-negative cancers – and to develop new approaches for treating them.

“The rapid increase in HPV-related head and neck cancers, noticeably in oropharyngeal tumors, has created an even greater sense of urgency in the field,” said

D. Neil Hayes, M.D., M.P.H, senior author of the study report and associate professor of medicine at the University of North Carolina (UNC) and the UNC Lineberger Cancer Center at Chapel Hill. Oropharyngeal cancer starts in the oropharynx, which is the part of the throat just behind the mouth. “We’re uncovering differences between tumors with and without HPV infection, and these new data are allowing us to rethink how we approach head and neck cancers.”

In the study, researchers performed genomic analyses on 279 tumors – head and neck squamous cell carcinomas (HNSCC) – from untreated patients. Approximately 80 percent of tumor samples were from individuals who smoked. The majority of samples were oral cavity cancers (61 percent) and larynx cancers (26 percent).

While only about 25 percent of head and neck cancers are linked to HPV infection, TCGA researchers confirmed that many patients with HPV-associated tumors have specific alterations of the gene *FGFR3* and mutations in the *PIK3CA* gene, which are also found in a much broader set of mutations in smoking-related tumors. In contrast, while the *EGFR* (epidermal growth factor receptor) gene is frequently altered in HPV-negative tumors in smokers, it is rarely abnormal in HPV-positive tumors. Such insights may help in developing potential therapies and biomarkers, noted Dr. Hayes.

Head and neck cancers comprise a constellation of tumors of the mouth, throat, larynx, nasal cavity, salivary gland and elsewhere that have frequently been attributed to tobacco and alcohol use in most patients. Some 90 percent are squamous cell carcinomas, which occur in the surface layers of cells in the body. An estimated 55,000 people developed head and neck cancer in the United States in 2014. Approximately 12,000 Americans die from the diseases each year. Head and neck cancers are common worldwide, with more than 600,000 cases diagnosed each year.

“The rising worldwide incidence of head and neck cancers makes these types of large integrated genomic analyses by TCGA vital to establish a more detailed understanding

of disease causes and behavior, and for the development of new treatment approaches,” said NIH Director Francis S. Collins, M.D., Ph.D.

TCGA researchers have uncovered new details about the potential role of the human papillomavirus in head and neck cancers.

Scientists found that more than 70 percent of head and neck cancers had alterations in genes for growth factor receptors (*EGFR*, *FGFR*, *IGFR*, *MET*, *ERBB2*, *DDR2*), signaling molecules (*PIK3CA*, *HRAS*) and cell division regulation (*CCND1*). These genes may play roles in pathways that control cell growth and proliferation, and for which therapies are either available or in development.

The investigators also discovered new clues about drug resistance in head and neck cancers. They found that genes affecting about 40 percent of such cancers form key parts of a pathway that helps determine cell survival and drug resistance. They showed that extra copies of the genes *FADD* and *BIRC2*, or mutations in or the absence of the *CASP8* gene in smoking-related cancers – all which affect the process of programmed cell death – may underlie the resistance of cancer cells to current treatments. Similarly, the absence of the *TRAF3* gene, or extra copies of a gene for the growth-promoting *E2F1* protein in HPV-related cancers, may also increase resistance.

The findings showed similarities between head and neck cancer genomes and other cancers, including squamous cell lung and cervical, indicating possible common paths of cancer development, and potential treatment opportunities. “It is surprising to see that head and neck tumor genomes are remarkably similar to cervical and squamous lung cancer genomes. They are from very different organs, but they show similar losses and gains of genetic material across tumors,” Dr. Hayes noted. These common genetic abnormalities belong to a pathway that protects cells from damage and stress.

“These novel findings help establish a genomic map of various head and neck cancers, provide new insights into other similar cancers and may further our [understanding of how viruses can impact](#)

continued on page 10

continued from page 9

disease,” said NHGRI Director Eric D. Green, M.D., Ph.D.

“While many head and neck cancers are preventable, they are increasingly common throughout the world, and often challenging to effectively treat over the long term,” said NCI Director Harold Varmus, M.D. “This type of broad analysis provides important new clues for future research and treatment directions.”

The TCGA Research Network has generated data and published analyses on a number of cancers, all of which can be found on the TCGA website, [www.cancergenome.nih.gov](http://www.cancergenome.nih.gov). TCGA-generated data are freely available at the TCGA Data Portal and CGHub.

This work was supported by the following NIH grants: P50CA097190, P50CA16672, U54 HG003273, U54 HG003067, U54 HG003079, U24 CA143799, U24 CA143835, U24 CA143840, U24 CA143843, U24 CA143845, U24 CA143848, U24 CA143858, U24 CA143866, U24 CA143867, U24 CA143882, U24 CA143883, U24 CA144025 and RO1 CA 095419. Additional funding was provided by the Bobby F. Garrett Fund for Head and Neck Cancer Research and the National Institute on Deafness and other Communication Disorders (NIDCD) Intramural Projects ZIA-DC-000016, 73 and 74.

Reference: The Cancer Genome Atlas Research Network. Comprehensive genomic characterization of head and neck squamous cell carcinomas. *Nature*. Online January 28, 2015. DOI: 10.1038/nature14129.

The TCGA Research Network consists of more than 150 researchers at dozens of institutions across the nation. A list of participants is available at <http://cancergenome.nih.gov/abouttcga/overview>. More details about The Cancer Genome Atlas, including Quick Facts, Q&A, graphics, glossary, a brief guide to genomics and a media library of available images can be found at <http://cancergenome.nih.gov>.

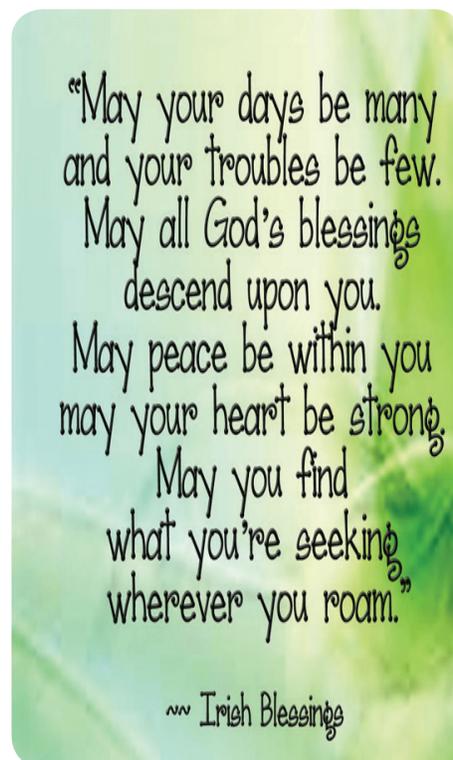
NHGRI is one of the 27 institutes and centers at the National Institutes of Health. The NHGRI Extramural Research Program supports grants for research and training and career development at sites nationwide. Additional information about NHGRI can be found at <http://www.genome.gov>.

NCI leads the National Cancer Program and the NIH effort to dramatically reduce the

burden of cancer and improve the lives of cancer patients and their families, through research into prevention and cancer biology, the development of new interventions, and the training and mentoring of new researchers. For more information about cancer, please visit the NCI website at <http://www.cancer.gov> or call NCI’s Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).

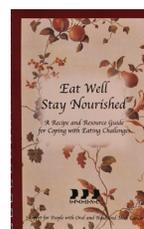
The NIDCD supports and conducts research and research training on the normal and disordered processes of hearing, balance, taste, smell, voice, speech, and language and provides health information, based upon scientific discovery, to the public. For more information about NIDCD programs, see the NIDCD website.

About the National Institutes of Health (NIH): NIH, the nation’s medical research agency, includes 27 institutes and centers and is a component of the U.S. Department of Health and Human Services. NIH is the primary federal agency conducting and supporting basic, clinical, and translational medical research, and is investigating the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit <http://www.nih.gov>.



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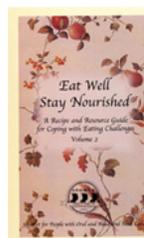
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