

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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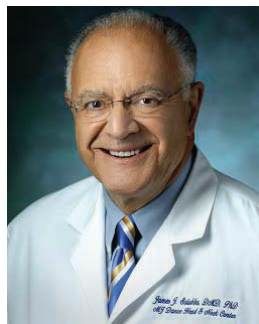


S•P•O•H•N•C
A PROGRAM OF SUPPORT
FOR
PEOPLE WITH
ORAL AND
HEAD AND NECK CANCER

Oral/Head and Neck Cancer Treatment and Salivary Dysfunction

James J. Sciubba, DMD, PhD

While many causes of inadequate saliva production are known, none are more sudden and devastating than that associated with radiation therapy in the management of malignancies of the head and neck region, most commonly squamous cell carcinoma of the oral cavity. Other malignancies including those arising in major



salivary glands, nasal and paranasal sinuses, larynx, and lymph nodes, either as a primary site or because of metastatic disease often rely on externally delivered doses of radiation as a stand-alone modality or as an adjuvant or supplement to surgical treatment and/or chemotherapy.

Many significant advances in radiation treatment, design and delivery have been made over the years, which are currently utilized on a routine basis, including routine implementation of intensity modulated radiotherapy (IMRT), three-dimensional CT guided treatment planning and delivery and proton beam therapy, all with fewer side effects (toxicity) compared to those treatments seen in the not-too-distant past. While significant side effects to treatment remain within our patient population requiring this form of management, these are generally less severe, more manageable, and better understood. Beyond surgery and radiation therapy, other forms of cancer treatment can affect saliva production including graft versus host disease, various types of chemotherapy, radionuclide therapy (radioactive iodine) in thyroid cancer management, and

certain forms of biologic therapy such as certain interleukins which are produced by inflammatory cells and have a role in regulation of the immune response. Emphasis here will be directed toward more commonly employed measures in oral and head and neck cancer treatment in the form of externally based radiation treatment.

Anatomically, salivary glands are separated into major and minor groups. Several hundred small, minor salivary glands reside deep to the mucous membrane surface, mainly in the oral cavity within the tongue, palate, lips, and cheeks (labial and buccal mucosa), and oral floor. Additional minor salivary glands reside in the oropharynx and larynx regions as well. The major salivary glands are paired structures on either side of the midline. Parotid glands are the largest, located in front of and below the ears, along either side of the jaw. Submandibular salivary glands reside beneath the tongue and are nestled between the midportion of the oral floor and jaw, while the smallest of the major salivary glands, the sublingual glands, are situated beneath the front portion of the tongue, also within the oral floor. Collectively these glands normally secrete or manufacture approximately 1 to 1.5 liters of whole saliva each day under resting and stimulated conditions. The process of secretion is complex, with interaction between the sympathetic and parasympathetic nervous systems regulating salivary flow rate, volume, and composition. Understanding the composition of whole or pooled saliva and its role in the maintenance of normal oral function including chewing, swallowing, taste perception, tooth integrity, speech production and articulation, bacterial and fungal composition and balance, and mucosal health is crucial in dealing with oral and head and neck cancer treatment-related salivary dysfunction. While saliva is composed of essentially 98% to 99% water, the balance consists of hundreds of substances and chemicals which are largely responsible for maintenance of oral and dental health and general daily oral function including eating, speaking, oral cleansing and clearance, digestion and prevention of several diseases or illnesses.

Actual damage to tumor cells as well as damage to normal cells from externally applied radiation sources fundamentally relates to entry of emitted radiation energy, usually photons ("X-rays"), from typical therapeutic machines into tumor fields. More recently in many locations, protons ("proton beam") have been used to perform the same function of tumor destruction. The protons are generated by a sophisticated machine or apparatus known as a *cyclotron*, which basically uses a high energy electrical field housed within two heavy electrodes to accelerate charged atomic or subatomic particles within a contained strong magnetic field. The high energy accelerated particles (protons or photons) are guided into a group of cancer cells (tumor) where there is a basic alteration of the makeup within cells. The entry energy then displaces electrons creating positively charged ions and highly reactive chemicals known as free radicals which in turn damage the

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NEWSLETTER EDITOR

Chris Leonardis

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inner working of the irradiated cells including their DNA, leading to cell death. Proton beam treatment versus photon treatment offers the advantage of not having an exit dose characteristic typically present in photon treatment, with the delivered protons more tightly confined to the tumor itself, versus photons, where there is less precise energy distribution and dose restriction. The ultimate result is much closer beam shape adapted to tumor tissue with more limited energy dispersal beyond the tumor and less resultant morbidity or so-called toxicity.

With typical doses of photon-based radiation therapy, and to date fewer cases of proton beam treated cases, used in the management of oral and head and neck cancer, excluding radiation sources placed directly into a tumor bed at surgery (brachytherapy), associated damage to the major salivary glands can result. Salivary tissues, which are exquisitely sensitive to radiation energy, generally suffer variable degrees of tissue damage with subsequent perceived and actual measurable salivary flow diminishment (xerostomia). The resultant salivary dysfunction, which is generally noted by the end of the second week of treatment, in most cases, results in approximately 50% salivary flow reduction, along with altered fluid composition. Changes in saliva composition plays a major role in a patient's perception as well as the reality of xerostomia and salivary dysfunction.

The actual chemical composition of saliva formed under normal circumstances is complex, with each gland group producing salivary fluid of differing composition and physical qualities (viscosity, specific gravity, etc.), all of which contribute to whole saliva's properties and overall functional characteristics. These groups of salivary constituents include organic and inorganic compounds such as, but not limited to, proteins, amino acids, enzymes, immunoglobulins/antibodies, electrolytes (sodium, potassium, phosphate, calcium, chloride, and low levels of fluoride), innate non-antibody substances, anti-bactericidal components, and other agents.

With treatment-associated (iatrogenic) salivary dysfunction ensuing, there are accompanying considerable alterations of general oral function within an otherwise normally efficient working of the rest of the body. At a "macro level" ensuing salivary loss or significant salivary gland dysfunction, with dry mouth often leading to or worsening treatment-associated mucous membrane soreness and pain (mucositis) and ulceration. Eating, swallowing, oral cleansing, and speaking can be affected by loss of saliva at an acute level, while taste abnormalities including temporary loss or blunting, generally follow in parallel. Later in the evolution of treatment-related oral cavity dryness/xerostomia, bacterial and fungal infections may develop. Periodontal (gum) disease, loss of tooth mineral with dental cavity formation (dental caries) and yeast infections (thrush) can be secondary to a shift of bacterial balance with higher numbers of disease-producing organisms surviving at the expense of less harmful normal bacteria, including normal oral fungal and bacterial balance within an altered "oral microbiome."

These possible compositional and functional changes relate to the components of saliva altered by flow and salivary volume reduction. The enzyme amylase and its several variants known as isoforms, for instance, aid in digestion of cooked starch, with its role in early digestion, is widely known. This enzyme class functions optimally in a narrow pH range, optimally 6.8. This is an important

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consideration in the patient with diminished salivary volume and flow where saliva's normal buffering capacity is reduced with a resultant more acidic environment. Many other salivary enzymes including lysozymes, peroxidases, lipases, and several others which serve important regulatory, protective, and metabolic functions.

Salivary *buffering power* or capacity is mediated by several components including *bicarbonates* (the most important buffering component), *phosphates*, and *proteins*. These components allow the oral pH to remain near neutral following shifts to either acidic or alkaline levels following meals or ingestion of foods or drinks where oral neutrality is disturbed and does so quickly. As a consequence, buffering helps maintain normal function and dental stability and mineralization. Similarly, the property of a chemical reaction known as *reduction* by salivary constituents is important as one of saliva's several antibacterial functions. Somewhat related to buffering, saliva also serves an extremely important role in maintaining integrity of the teeth by way of several constituents including *calcium*, *phosphate*, *proline-rich glycoproteins*, *statherins* and other compounds. The latter substances (statherins) are important in inhibiting adherence of bacterial film/biofilm and plaque to tooth and mucous membrane surfaces. Thus dental decay-causing bacteria fail to colonize the tooth surfaces, with fungi also less likely to adhere to mucous membrane surfaces. Beyond statherins, *Histatins* deter fungal and bacterial metabolism by directly invading and inactivating these harmful organisms. Other salivary components serving important roles in maintaining low levels of bacteria, fungi and viruses and maintaining oral health include *lactoferrins*, *mucins*, *cystatins*, certain *glycoproteins*, components of the innate immune system including *defensins*, *canthelidins* and several other protective constituents. The absence or diminishment of these can lead to development of clinical disease including yeast overgrowth (thrush), dental decay (caries), periodontal/gum disease and generalized oral discomfort and dysfunction. While quite technical, one can appreciate the vast complexity of salivary composition and the role saliva plays in maintaining oral health or so-called homeostasis.

Management of dry mouth

Established dry mouth or xerostomia resulting from oral and head and neck cancer treatment remains a difficult problem for patients and their medical and dental caregivers. Dealing with xerostomia generally relates to a combination of fluid compensation or replacement, adequate but not excessive hydration, use of lubricants and moisturizers, by taste stimulation to help overcome taste alterations (gustatory stimulation) with use of sugar-free lozenges or chewing gum, dental decay prevention strategies with use of prescription strength sodium fluoride toothpaste and fluoride rinses. Finally, the prescription drugs *cevimilene* (Evoxac®) and *pilocarpine* (Salagen®) have an important role in stimulating saliva production in many patients which are often but variably helpful.

An electrical stimulation approach used in the past and refined more recently, includes application of electrodes over the parotid gland region by a technique known as TENS, or transdermal electrical stimulation. Recently introduced and previously available intraoral electrical stimulation devices hold promise as well, though cost may be a factor. These devices are well tolerated by most. Most promising is a newly available battery-powered device (Sailpen®) as a safe, non-pharmaceutical salivary stimulant, available by prescription through the manufacturer, Saliwell Ltd.

The role of acupuncture, in qualified hands, has also been helpful to many as a non-invasive, non-prescription management form with variable levels of success.

As stated, the role of this precious and often under-recognized body fluid is an enormous one with health and functional implications in its absence or when it is severely limited in volume.

Furthermore, management of the results of dry mouth such as fungal or yeast overgrowth include the use of topical antifungal drugs: *miconazole*, *nystatin*, *clotrimazole* (Mycelex®) troches and systemic antifungal drugs such as *fluconazole*. Prevention of dental decay remains a challenge, with routine dental visits being necessary in addition to daily oral hygiene measures and use of high concentration of sodium fluoride toothpaste and remineralizing products by prescription. Your dentist can construct soft, flexible

mouth trays as a carrier for fluoride gel to help remineralization of teeth and as a cavity prevention strategy.

Not to be ignored and appreciated is the very important role of commonly used systemic medications that are in common use by many individuals for management of many concurrent or chronic medical conditions capable of producing dry mouth, or which have a definite relationship to salivary dysfunction as a stated side effect. Prior to radiation therapy such effects of many routinely used medications by many patients may not have been fully present or were less noticeable. In effect the perfect storm of drug-related side effects and radiation treatment directly involving salivary glands can become a profound problem, unless addressed in a timely and effective manner. Drug classes that are commonly associated with dry mouth side effect profile include antihistamines, decongestants, antidepressants, antipsychotics, sedatives / anxiety control medications, blood pressure (hypertension) management agents and allergy and cold medications.

Post-radiation Return of Salivary Function

The often-posed question regarding cancer treatment of any sort is estimating or describing the expected duration of treatment-associated morbidities or side effects. Each form of oncologic or cancer-related treatment including surgery, radiation therapy and chemotherapy carry well-known long term side effect profiles patients must be aware of and prepare for. The expected duration of radiation-related dry mouth varies widely with most patients reporting degrees of significant return of function, usually beginning slowly after approximately 6 months, but usually not at pretreatment levels, thus degrees or levels of xerostomia must be viewed as permanent, but not necessarily life-altering with proper understanding, routine management, and follow-up care.

An exhaustive list of available over the counter preparations and products can be found in nearly any pharmacy or large grocery store. Specific to our patient population, SPOHNC has developed an extensive over the counter and prescription Product Directory which lists many aids targeting dry mouth, and treatment-associated mouth soreness and overall

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symptoms. This guide is available as a benefit of SPOHNC membership and can be accessed by joining as a SPOHNC member through the website at www.spoync.org or by contacting the organization at 1-800-377-0928.

Access to clinical trials has long been a focus of the SPOHNC community outreach effort. By accessing the SPOHNC website one can find a large variety of information including clinical trials and the latest advances in oral and head and neck cancer. Access to clinical trials can be found through the *Clinical Trials Navigation Service* under the Cancer Information dropdown on the SPOHNC website home page. Once on the Cancer Information page, clicking on the SPOHNC Clinical Trial Navigation Service “read more” will connect you with Clinical Trial Navigators who will help you quickly search for clinical trials that match your specific diagnosis, stage and treatment history. The same Navigator will follow up with you to make sure you are successfully connected to the studies and doctors that interest you. The Clinical Trials section also offers relevant and up to date information specific to a range of clinical concerns, as well as serving as a learning resource.

Finally, for those interested, a recent detailed and comprehensive publication is now available with in-depth discussions and analysis of head and neck cancer radiation therapy and its effects and management options. This reference (Mercadante V, et al. in the *Journal of Clinical Oncology*, can be accessed on line at <https://doi.org/10.1200/JCO.21.01208>.

Editors Note: Dr. Sciubba received his dental undergraduate education at Fairleigh Dickinson University, a Ph.D. in Pathology from the University of Illinois, followed by a fellowship

*in Oral & Maxillofacial Pathology at the ADA. He has served as a full Professor in the Departments of Otolaryngology-Head and Neck Surgery, Pathology and Dermatology at The Johns Hopkins School of Medicine and at the SUNY Stony Brook, School of Dental Medicine. Dr. Sciubba was the Director of Dental & Oral Medicine at The Johns Hopkins Hospital as well during his tenure at Johns Hopkins. Prior to moving to Johns Hopkins, Dr. Sciubba served as Emeritus Chair of Dental Medicine at The Long Island Jewish Medical Center and was accorded Emeritus Professor recognition at Stony Brook University School of Dental Medicine in 1999. He has over 40 years of experience with oral and head and neck cancer patients and those with oral diseases and conditions as a clinician and pathologist and has published extensively in the areas of oral cancer, oral mucosal and salivary gland diseases, jawbone pathology and dental education as author or co-author of seven textbooks, including seven editions of the *Textbook of Oral Pathology* (Elsevier) and over 300 peer reviewed papers, abstracts and chapters, and has lectured extensively throughout the US, Central and South America, Europe and Asia.*

Dr. Sciubba is presently President of Support for People with Oral and Head and Neck Cancer (SPOHNC) and was instrumental in the founding of this organization in 1991, as well as a co-founder of The Sjogren's Syndrome Foundation in 1983.



Advice from a Caregiver “Here for You”

Here’s something I put together given my experience in the caregiver role. I share these with people if asked how to approach being a caregiver.

- H** - Have Patience - This is a learning process for you and the patient.
- E** - Everyone wants to know. Designate a spokesperson to share info and respond to calls, etc.
- R** - Read the two books that are recommended (Meeting the Challenges of Oral, Head & Neck Cancer and We Have Walked in Your Shoes). Both are available through SPOHNC.
- E** - Every patient has difficult moments. You might have to get tough and push them.
- F** - Friends and Family - It will take a Village - get yours in place and ask for support.
- O** - Open your mouth! Do not be afraid to ask! Any question is OK! Ask them to spell the big words!
- R** - Roles change - you will wear many “Hats”- some of them will be new to you!
- Y** - You need to take time for yourself - Breathe - do something that makes you feel good.
- O** - One important phone call - SPOHNC! You and your patient can receive support!
- U** - Use your smile! Nurses and doctors will be your best friends. Treat them with respect and say thank you!

~ Connie Lunt
Caregiver and NSVN Volunteer



YOU are important to SPOHNC. That’s why we created this ongoing survey. We want to know how we can be better – for YOU. Please access the survey by scanning the QR code using your mobile phone. You can also take this survey at: tinyurl.com/SPOHNC



Thoughts from a Caregiver

TEN THINGS

Our story is complex and long with more turns and twists than I care to think about. It involves warriors, passionate helpers both professional and not, lots of prayers, patience, faith and fortitude. It has taught me so much.

The background is my husband was diagnosed with Human Papillomavirus (HPV) tonsil cancer in March 2015. We have few family members locally and at the time I was helping my mother, who at age 94 still lived independently. In short, we felt we were on our own. I fortunately was retired as of 2012, having taken the earliest full retirement date that was afforded to me. We did not know one thing about this type of cancer nor we did not know about SPOHNC at the time.

The shock of that biopsy and diagnosis, and coping with so many days that followed, still remains surreal and traumatic for me. My husband was 62 at the time and he was the picture of health. The medical staff was reassuring about outcomes. The word 'cure' was said often. As it turned out, since my husband had a reoccurrence around that same area where the tonsil was at nearly the 5-year post surgery mark, our journey found, and still finds, us in the smallest of percentages of HPV cancer patients and we battle on. The details are brutal. I will spare you those. I am writing today because I wish that I could tell 2015's version of me a few things, things that would have helped me/us. Plus, for any newly diagnosed folks, take heed from someone who is up close and personal with this cancer. ***Like everything in life, when you know better, then you do better and your life becomes more your own again.***

Ten Things

(I wish I had known in March 2015)

1. Appreciate simple things. For example, eating, swallowing, drinking water, tongue movement, speech, your airway etc. We tend to not give any of these even a passing thought; however, few things hit home harder than day after day of not being able to enjoy a simple, quiet, stress-free meal with your spouse. The humanity of it is startlingly visceral and sad. I have never taken these things for granted again.
2. Seek an integrated medical team. They are literally and figuratively life savers. They will coordinate your care for you which allows you to proceed seamlessly from appointment to appointment and treatment to treatment. You won't have to schedule, make phone calls or try to work through the medical system. Hopefully your medical team will also have an active tumor board to ensure continuity of treatment and care across medical specialties. Taking responsibility for all of the medical logistics away from me was the biggest relief.
3. Listen to your medical team but listen to your gut too. Don't hesitate to call the doctors, even after hours. You might save a life. Cancer doctors expect those after-hours calls. Be an advocate and an aggressive one, if need be. Let 'better safe than sorry' be your mantra.
4. Do not let cancer isolate you. Family and friends will try mightily to help you and to understand. Unfortunately, or fortunately for them, they will never grasp what you are going through. Plus, you might not be capable of articulating what you need. That means self-care is a must for the patient and the caregiver. This 'race' is also a marathon not a sprint. So, take the meds, go for the counseling, find the SPOHNC support group...do what it takes to keep putting one foot in front of the other regardless of your role in the cancer fight.
5. Get a GI feeding tube. A feeding tube is a literal life saver. Reluctance is silly. Better to have it and not need it than vice versa. My husband lost 50 pounds, that he did not have to lose, WITH a GI feeding tube.
6. Dreading scans is normal and scan-anxiety is real. It is horrible every single time no matter where you are on the journey. I wish this were not true.
7. Staying in the present is critical. Even a small issue, real or imagined, may take you right back to the worst place in your life. This is one description of PTSD. There will be days that it will be nearly impossible to focus on one day at a time. Expect those days and know that they too shall pass.
8. Do not neglect yourself if you are a caregiver. You might feel forgotten. Caregiver burn out is real so make yourself take a respite break wherever you can even if it is just a quick cup of coffee with a friend or a visit to a favorite quiet spot alone for a few moments. The recharge will help you pick up your battle armor again and to fight on. Taking respite is not a selfish act.
9. Progressing through your treatment and recovery might not be linear. In fact, things might get worse before they get better. Expect setbacks and hiccups. They will pass.
10. Stop Googling and ask the professionals for their input. The internet does not know you. Truth and data always beat speculation, misinformation and shared on-line horror and 'war' stories. Nothing positive is gained from this type of on-line speculation about your situation.

Lastly, I'll offer a public service announcement of sorts. Do not accept the stigma that might be associated with HPV cancers. Talk to everyone about vaccinations. An informed person will make a better decision and thanks to you, they might have a better grasp of what this cancer can do to a life or lives since as the saying goes, nobody fights alone. You might encounter blank stares and speechlessness. Do not let that stop you. The stakes are simply too high.

Thanks for 'listening'. Fight on. We cannot let cancer win.

~ Tina Benscoter, Caregiver &
Penn State SPOHNC Head and Neck
Cancer Support Group member

**10 THINGS I
KNOW NOW
THAT I WISH I
KNEW BACK
THEN ...**



“Like” SPOHNC on Facebook

HEAD AND NECK CANCER NEWS

Symposium Highlights Advances in Personalized Head and Neck Cancer Treatment

On October 8, 2021, Boston University School of Dental Medicine, Dana-Farber Cancer Institute and Beth Israel Deaconess Medical Center presented a virtual Head and Neck Cancer Symposium called “Targeting the Future: Personalized Approaches for Head and Neck Cancer.” Leading researchers in the field gave presentations in four key areas of promise:

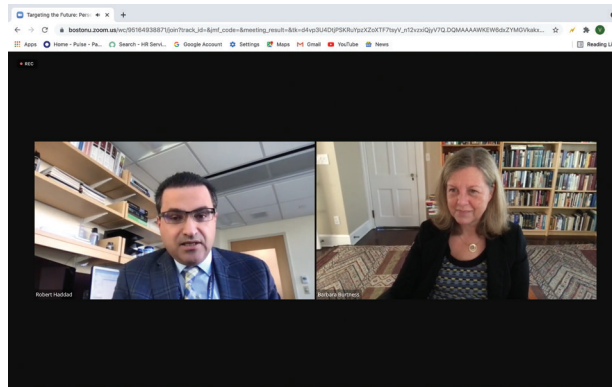
Emerging Technologies

Clinicians are repurposing technologies in the operating room to improve accuracy:

- Augmented reality tracking systems are providing surgeons with real-time robotic surgery guidance. Fluorescent Guided Surgery, where a fluorescent instrument helps surgeons illuminate through to a lesion’s undersurface and highlights residual disease, lets surgeons pinpoint margins during procedures. Researchers hope to introduce systemic fluorescent imaging agents that bind to a tumor’s primary and regional sites, making it easier to identify positive margins and lymph nodes.
- In the lab, researchers are using multiplexed immunofluorescence assays to sequence 500,000 individual cells in each tumor sample. Researchers are especially studying two types of immune system T cells, CD4 and CD8, in relation to tumor cells. Also of interest: how so-called “link” RNAs interact with p53 in the tumor suppression process and affect tumor-free survival.

Human Papillomavirus (HPV) and Deintensification

Current head and neck cancer treatment guidelines fail to distinguish between patients whose tumors are HPV positive (HPV+) and HPV negative (HPV-), even though patients with HPV+ tumors have a higher survival rate (90% at 3 years). As a result, younger



CAPTION: Above: Session Chair Robert Haddad, MD, Disease Center Leader; Head and Neck Oncology Program, Dana-Farber Cancer Institute and Professor of Medicine, Harvard Medical School, with Keynote Speaker Barbara Burtness, MD, Professor of Medicine (Medical Oncology) and Co-Leader of Developmental Therapeutics Program, Yale University.

HPV+ patients may receive more treatment than they need and endure treatment side effects for decades. Researchers are studying which HPV+ patients may benefit from less toxic treatments at lower doses (“deintensification”):

- Vaccines to prevent HPV may already be reducing the development of head and neck cancer cases caused by HPV 16, 18, 6 and 11. In one Costa Rican study, the HPV vaccine demonstrated 93.3% efficacy with only one HPV 16/18 infection occurring among the vaccinated group, compared with 15 cases in the unvaccinated control group.
- In a separate study, blood samples taken from a control group without a history of cancer showed that people whose blood samples contained HPV16 E6 antibodies had a much higher rate of developing oropharyngeal cancer. This blood marker was visible as early as 12 years before diagnosis. Researchers hope to apply this finding to monitor at-risk populations.
- Measuring the circulating tumor HPV DNA (“CtHPVDNA”) in an HPV+ patient’s blood may help clinicians determine if the patient is responding to treatment. CtHPVDNA is released in the blood as tumor cells die. In one

study, all nasopharyngeal patients who cleared CtHPVDNA from their blood by week four of treatment remained free of recurrences. Monitoring patients with blood tests every 3 months could provide a reliable biomarker of how patients’ tumors are responding.

- Researchers are looking at less toxic treatments for carefully selected HPV+ patients. While this area is promising, clinicians need to carefully test patients for biomarkers and conduct surgical staging to make sure that treatment de-escalation is appropriate.

Molecular Approaches to Personalized Therapy

Manipulating the microenvironment within a tumor may help scientists tailor strategies for individual patients:

- Researchers are investigating whether high amounts of the protein beta-catenin and its interplay with other epigenetic regulators within a tumor affect a patient’s prognosis. Some studies also indicate that the transcription factor SOX2 may, over time, be a critical driver of tumor initiation.
- Pre-malignant stem cells rely on high amounts of the amino acid serine, studies show. Depriving these cells of serine may be tumor-suppressive.
- Perineural invasion can be an indicator of poor prognosis in some patients, and researchers have found that having a high density of nerves at a close distance to a tumor promotes tumor growth. Researchers are using immunohistochemistry (IHC) to enhance detection of perineural invasion and improve outcomes.

Novel Approaches to Immunotherapy

Head and neck tumors contain specific antigens that may make them responsive to immunotherapy:

- Scientists are collecting patients’ tumor and blood samples to look for myeloid

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Visit the SPOHNC website at www.spohnc.org

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and neutrophilic cells related to tumor-mediated immune suppression. Scientists hope to use immunotherapy to prevent the transformation of leukoplakia, a white plaque some patients have in their mouths, into full-blown head and neck cancer. Currently patients must undergo regular biopsies to monitor the condition. Leukoplakia has not responded to topical agents in studies but could be a target for immunotherapy.

- Many trials are enrolling to study the integration of PD-1 inhibitors in the treatment of head and neck cancer. Avelumab, nivolumab and ipilimumab are just three immunotherapy drugs that may hold promise when combined in drug “cocktails”. Patients with PD-L1 tumor markers especially showed a response to immunotherapy drugs, which have fewer severe side effects than chemotherapy.
- Immune Effector Cell (IEC) Therapy, in which cells are stimulated to produce an immune response, is already being used to treat lymphoma and other solid tumors. Scientists are now working to identify tumor-specific antigens and are investigating the use of tumor-infiltrating lymphocytes (TILs) in head and neck cancer. One exciting area of investigation: Killing virus-infected cells to exhibit an anti-tumor response.

The coming years promise to be exciting ones in the field of head and neck cancer therapy research, as new technologies make it possible for researchers to get inside tumors in ways never before possible.

Read more about the Symposium here: bit.ly/BostonHeadNeck

~ Valerie Goldstein, Survivor and
SPOHNC Boston,
MA Chapter Facilitator

*“I understand the importance
of support, especially in
the time of crisis.
You have fostered hope...”*

~ A.B.

Happy Thanksgiving from “Eat Well Stay Nourished A Recipe and Resource Guide For Coping With Eating Challenges”

Compiled and Edited by Nancy E. Leupold, Founder, in memoriam

Cranberry Chicken (from Volume One)

3 lbs. meaty chicken pieces
1 (16 oz.) can whole berry cranberry sauce
1 onion, chopped
1 tsp. cinnamon
1 tsp. ginger
1 c. orange juice
Vegetable oil

Bread chicken with flour, salt and pepper. Saute chicken pieces in oil and arrange in baking pan. In a saucepan, combine cranberries, onion, seasonings and orange juice. Heat until cranberry gel liquefies. Pour over chicken and bake at 350 degrees for 45 minutes. Serve over rice. Yields 8 - 8oz. servings. 280 calories/serving.



~ Member of SSF, PA

Elsie's Torte (from Volume Two)

½ butter
1 ½ c. sugar
1 c. flour
4 eggs, separated
1 tsp. baking powder, sifted
4 Tbsp. milk
1 c. whipping cream
1 tsp vanilla or almond extract



Cream together butter and ½ cup sugar. Add 4 egg yolks and beat. Add flour, baking powder and milk. Mix until smooth. In separate bowl, beat 4 egg whites until fluffy, gradually adding remaining sugar. Beat until stiff peaks form (meringue). Set aside. Grease and flour two 9-inch round pans. Pour batter into both pans. Add meringue mixture to both pans. On top of cake, add some slivered almonds (optional). Bake both pans at 350 degrees for 40 minutes. Cool in pans. Remove and place one layer upside down on a plate. For filling, beat together whipped cream and vanilla or almond extract. Smooth onto upside down cake. Remove second cake from pan and place meringue side up on top of other cake. Enjoy! Serves 8. 398 calories/serving.

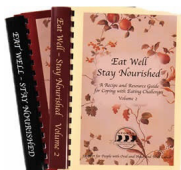
~ Nyra T., NY



***Eat Well Stay Nourished
A Recipe and Resource
Guide
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compiled by Nancy E. Leupold,
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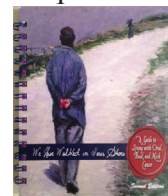
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**are pleased to share the recording of the
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held on Thursday, August 19, 2021.
(Learn more about dry mouth)**

*View the recording at
<https://www.youtube.com/watch?v=0diX2-naOH4>*

*"You are doing a wonderful job
by everything you are doing and have been doing.*

*Thank you so very much
from a grateful head and neck cancer patient!"*

~ Laurretta M.

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NEWS FROM THE BOARD ROOM

Eugene Myers, MD, FACS, FRCS, Edin (Hon) Conference Chair Guest of Honor

Highly esteemed member of SPOHNC's Board of Directors, Eugene Myers, MD, FACS, FRCS, Edin (Hon) was recently recognized by the American Head and Neck Society as the **Conference Chair Guest of Honor**, at the American Head and Neck Society 10th International Conference on Head and Neck Cancer, held virtually.

Robert Ferris, MD, PhD, AHNS 2021 Conference Chair and member of SPOHNC's Medical Advisory Board, presented Dr. Myers with this esteemed honor. He shared these heartfelt words about his colleague, with SPOHNC.

"Dr. Myers is an icon in the field of head and neck cancer surgery, including being the chairman who hired me out of training over 20 years ago. It gave me tremendous pleasure to recognize all that he has done for our head and neck cancer patients here in Pittsburgh, and across the world due to his extensive educational and training activities and outreach to other physicians across the world caring for these patients."

Dr. Eugene N. Myers comes from a long line of physicians including his Grandfather, his Father and three Uncles. His Father, David, was the Chairman of the Department of Otorhinology in the Temple University School of Medicine.

Dr. Myers received a B.S in Economics from the Wharton School of the University of Pennsylvania and his M.D. from Temple

University School of Medicine. He interned at Mt. Sinai School of Medicine in New York City followed by a residency in Otolaryngology at the Massachusetts Eye and Ear Infirmary in Boston. This was followed by military service as a Captain in the U.S. Army stationed in Frankfurt, Germany. He then served as a Special Fellow in Head and Neck Surgery with Dr. John Conley in New York City.

Dr. Myers was appointed Chairman of the Department of Otolaryngology in the University of Pittsburgh School of Medicine in 1972 and under his leadership transformed it into a world-renowned Department. He estimates that he did 9,000 operations during the 33 years as Chairman. He has made many contributions including the development and implementation of the treatment method to properly manage patients who have extracapsular spread of cancer in their cervical lymph nodes.

Dr. Myers academic achievements include the publication of more than 300 peer reviewed articles, 20 textbooks, including the popular Cancer of the Head and Neck and Operative Otolaryngology-Head and Neck Surgery, 150 book chapters, more than 750 lectures, panels and round tables, including 48 eponymous lectures.

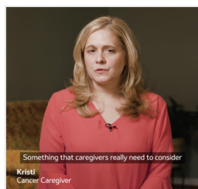


Dr. Myers is Past President of the American Board of Otolaryngology, the American Academy of Otolaryngology-Head and Neck Surgery, the American Society of Head and Neck Surgeons, the American Laryngological Association, and the Pan American Association of Otolaryngology-Head and Neck Surgery. He was the founder of the International Department of the American Academy of Otolaryngology-Head and Neck Surgery and organized a worldwide network of National Societies which includes the AHNS. He is an Honorary Member of more than 20 National Societies including the Caribbean Association of Otolaryngology. He has been an enthusiastic supporter of CAO since 1996.

Dr. Myers remains deeply involved in international affairs including membership in the International Steering Committee of the AHNS. He is also President of the Board of Directors of Pittsburgh Festival Opera and a member of the Board of Directors of the Eye and Ear Foundation, as well as SPOHNC (Support for People with Oral and Head and Neck Cancer.)

Dr. Myers and his wife Barbara have been married for 65 years. They have a daughter, Marjorie, who is an Executive Recruiter and a son, Jeffrey, who is the Alando Ballantyne Professor and Chairman of the Department of Head and Neck Surgery in the MD Anderson Cancer Center, and 5 overachieving Grandsons, all of whom he loves very much.

Caring for Yourself and Others



"If you're going to be an advocate for somebody and taking care of somebody, you have to take care of yourself." This #CaregiversAwarenessMonth, remember that prioritizing self-care during a difficult time is so important. #MerckPartner

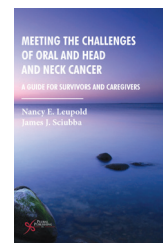
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Sister Mary Ryan *in memoriam*

SPOHNC shares its deep sadness upon learning of the passing of longtime SPOHNC volunteer and former Facilitator of the Terre Haute, Indiana SPOHNC Chapter support group, Sister Mary Ryan, on August 23, 2021.

Sister Mary was a gracious, gentle woman who brought along her experience as an oral cancer survivor and her compassion as a woman of great faith, when she formed her local chapter of SPOHNC. She was also a dedicated volunteer for SPOHNC's National Survivor Volunteer



Network since 2015, supporting newly diagnosed patients along their cancer journey. In 2020, it was SPOHNC's great honor to recognize Sister Mary for her 10 years of dedication and support.

Sister Mary entered the Congregation of the Sisters of Providence on Aug. 16, 1989 and professed Final Vows July 20,

1996. She earned a bachelor's degree from Salem State University. In 1998, when she received her first diagnosis of oral cancer, her life changed forever.

She had just graduated from Dominican University in Illinois with a master's degree in library and information sciences and was heading back to her home state of Massachusetts to minister as a librarian.

Despite the diagnosis, Sister Mary traveled to Massachusetts for her ministry and received treatment. While she was in Massachusetts, she joined the local Support for People with Oral and Head and Neck Cancer support group, where she found hope and was inspired by the kindness of the group, who supported her along the way.

In 2005, Sister Mary was asked to come to Saint Mary-of-the-Woods, Indiana, to serve as the Congregation archivist. She accepted the position and moved to Indiana, where she sought out the support of a SPOHNC Chapter support group there. The

closest one was in Indianapolis.

Since that was a distance away, Sister Mary started her own SPOHNC Chapter support group in Terre Haute in 2009. She remained steadfast in her commitment to providing hope, just as those in the Massachusetts SPOHNC Chapter had done for her. While she thought she was doing something to support others, Sister Mary also discovered that the group was supporting her in ways she never realized would come to pass.

As Sister Mary's health declined, she never failed to choose life. She did volunteer ministry on campus and at the county library in West Terre Haute until the pandemic, participated fully in community life, and stayed in touch with many survivors from the Terre Haute SPOHNC Chapter support group.

Sister Mary was a bright spirit and a shining star in the SPOHNC family. Her presence will be missed. We will keep Sister Mary in our thoughts and prayers, safe in the knowledge that she is resting now, and is at peace.

YOU ARE INVITED

TO A TRANSFORMATIVE WEBINAR with Stage IV Throat and Neck cancer survivor/Thrifer of 16 years, Denise DeSimone. Denise is an author, mentor, inspirational



speaker, and a cancer wellness coach. Her first book, FROM STAGE IV TO CENTER STAGE has helped thousands of people. She is also the producer and director of her new film, THE DOCUMENTARY-FROM STAGE IV TO CENTER STAGE.

Spending time with Denise will be powerful, enlightening and fun. Much of her work focus is helping people turn challenges into doorways of transformation. Cancer is a challenge. Cancer does not have to DEFINE the rest of our lives. Cancer is a wakeup call, giving us reason and the impetus to REDESIGN the rest of our

lives. REDESIGN your L.I.F.E. & Live In Full Expression. Walk through the doorway of transformation into the life you deserve. Denise will share her new L.I.F.E. program and how you can participate. Living fully expressed means different things to different people. What does it mean to you?

Please join us on Wednesday, December 8th @ 7:00 p.m. EDT. There will be time for Q & A toward the end of the hour.

Please claim your spot now by using either the QR code or copy and paste this address into your browser. <https://denisedesimone.kartra.com/page/deniselive>

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CHAPTERS OF SPOHNC

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

PLEASE NOTE: Many Chapters are not holding meetings in person at this time due to COVID-19.

Many groups have found other creative ways to support one another during this time of need.

Please call to SPOHNC at 1-800-377-0928 to find out more information.

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~ Mark K.



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