

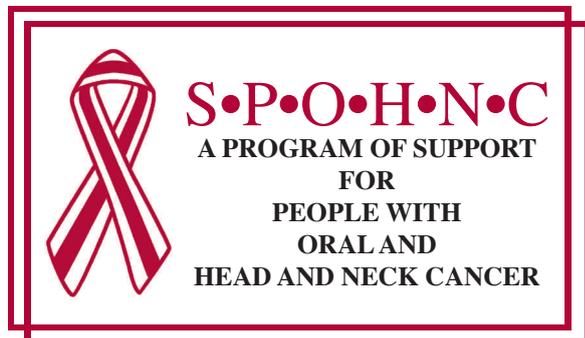
NEWS FROM S·P·O·H·N·C



VOL. 25 NO. 8

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

MAY 2016



NIDCR Research to Help Cancer Survivors Overcome the Problem of Dry Mouth

Gerianne Piazza, M.A.

For people who have been treated with radiation therapy for oral, head, and neck cancer, dry mouth (xerostomia) is one of the most serious and life-changing side effects. When high-energy rays are aimed at the mouth and throat to kill cancer cells, the cells in the salivary glands can be damaged as an unwanted side effect. The damaged cells no longer allow saliva to be manufactured and released by the salivary glands. This inability to release saliva may occur soon after treatment and persist years later. For some oral cancer survivors, the salivary glands may never work right again.

A healthy adult produces about a liter of saliva each day. Many of the estimated 300,000 Americans who have survived oral, head and neck cancer treatments often produce much less than that. A dry mouth makes it challenging to talk, chew food, and swallow, and makes tooth decay, painful ulcers, and other problems in the mouth much more likely. Although the health care team can offer ways to relieve dry mouth, such as moistening the mouth with a saliva substitute or ice chips, aside from prescribing salivary stimulants there is no cure for this very common problem.

However, researchers all over the world are in pursuit of better treatment options for people with dry mouth. In Bethesda, Maryland, alone, four research laboratories that are part of the National Institute of Dental and Craniofacial Research (NIDCR) are working to solve the problem of dry mouth. NIDCR — which is part of the National Institutes of Health (NIH) — is the lead federal agency for scientific research to improve the nation's dental, oral and craniofacial health.

NIDCR scientists are seeking new therapies for dry mouth from a variety of angles in the lab and clinic:

- Using gene therapy to restore gland function
- Finding potential drug targets by discovering further details of how salivary glands work
- Studying living tissues in three dimensions to create an artificial salivary gland
- Regenerating salivary gland tissue from progenitor cells

NIDCR's investments to discover better treatments for dry mouth may help not only cancer survivors but also people with other conditions, such as autoimmune diseases that destroy salivary glands.

Using Gene Therapy to Restore Gland Function

NIDCR is investigating the safety and effectiveness of gene therapy, which is a method that uses a virus to deliver a gene to cells in the body. The new clinical study that is about to begin will show whether gene therapy can be used to relieve dry mouth in people whose salivary glands have been harmed by radiation therapy. NIDCR will soon select and enroll about 50 oral, head, and neck cancer survivors in this study.

Several years ago, gene therapy using a virus known as adenovirus was tested and shown safe with 11 head and neck cancer survivors at the NIH Clinical Center. The pioneer of this approach—Bruce Baum, D.M.D., Ph.D.—used the gene for the water channel protein (aquaporin-1). This protein forms pores in the cell membrane so that water can flow in and out of the salivary gland cells. After the aquaporin-1 gene was inserted into cells in the salivary gland via the adenovirus, about half of the cancer survivors noticed an increase in salivary flow and relief from dry mouth.



Since Dr. Baum's retirement from NIDCR in October 2011, John A. Chiorini, Ph.D., chief of NIDCR's Adeno-Associated Virus Biology Section of the Molecular Physiology and Therapeutics Branch, and his research team have been developing another method of delivering the aquaporin-1 gene to damaged salivary glands. Dr. Chiorini's team chose a virus called AAV (adeno-associated virus) which may work better than adenovirus by

persisting longer than adenovirus in cells and by having a lower chance of side effects. The lab studies conducted with research animals were promising: the AAV-delivered aquaporin gene restored the saliva-producing ability of the damaged glands.

The planned clinical study with human volunteers will help show whether gene therapy can increase saliva production

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in people whose salivary glands have been harmed by radiation therapy. NIDCR investigators will use a syringe to deliver a solution containing the gene therapy into one gland inside the mouth. More information about this study is at <https://clinicaltrials.gov>. The study is called, “Safety of a Single Administration of AAV2hAQP1, an Adeno-Associated Viral Vector Encoding Human Aquaporin-1 to One Parotid Salivary Gland in People With Irradiation-Induced Parotid Salivary Hypofunction.” The study is expected to last about three years.

To learn how to qualify as a volunteer for this Phase 1 study, cancer survivors or their doctor may contact Dr. Chiorini (301-496-4279 or jchiorini@nih.gov) or NIDCR Clinical Operations Manager Tammy Yokum, MSN, RN (301-827-1138 or yokumtk@nidcr.nih.gov).

Discovering How Salivary Glands Work

Through the methodical identification and description of genes and molecules in salivary gland cells and through the identification of natural promoters of salivary flow, NIDCR hopes to devise ways to boost production of saliva in people with dry mouth.



Deputy Scientific Director James E. Melvin, D.D.S., Ph.D., Chief of NIDCR’s Secretary Mechanisms and Dysfunction Section and an internationally renowned investigator, has made landmark contributions to the field of salivary gland physiology and leads this effort.

In healthy adults, most (about 90 percent) of saliva is secreted by the three major salivary glands, which are known as the parotid, submandibular, and sublingual glands. The rest is produced by minor salivary glands. NIDCR researchers have compared the function of the three types of major glands and determined that each type of gland has unique functional properties. They used molecular methods to help identify what might explain their differences in function.

Dr. Melvin’s team is identifying the genes and proteins responsible for salivary flow, and they are employing state-of-the-art scientific research methods—such as molecular biology, RNA sequencing, gene modification, and proteomics—to find therapeutic targets. Such targeted therapies would relieve dry mouth by reversing the saliva flow problems that cancer patients have after radiation therapy. The goal is to find drugs that can activate the secretion of saliva in patients with damaged glands.

Studying Living Tissues in Three Dimensions

For more than 65 years, scientists have been extracting salivary glands from mouse embryos and observing how they grow in living tissue culture. About 12 days after conception, a bud near the tongue forms in the embryo. This bud branches into three or four buds, which continue branching until the embryonic gland resembles a cluster of grapes. Shortly after that, the solid cores hollow out to form ducts so that the gland can release saliva through ducts into the mouth.



Kenneth M. Yamada, M.D., Ph.D., is

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an NIH Distinguished Investigator and Chief of NIDCR's Laboratory of Cell and Developmental Biology. His team studies how groups of cells interact with their environment within developing mouse embryos. They investigate which cells and molecules are essential for the salivary glands to form properly. For example, they examine how certain cells migrate and self-organize to form buds and ducts so that saliva can be made, transported within the gland and released into the mouth.

By identifying the molecular mechanisms involved in how the salivary gland forms its three-dimensional grapelike clusters and ducts, Dr. Yamada's team is providing the scientific building blocks so that damaged salivary glands might be regenerated or artificial glands might be created using tissue engineering techniques. In fact, Dr. Yamada and collaborators—including Dr. Baum, have already been issued a patent for an artificial salivary gland (United States Patent No. 6743626).

Regenerating Salivary Gland Tissue

About 40 years ago, it was discovered that while the branches and cavities of the salivary gland are forming in the embryo, nerves also develop. These nerves send out projections that weave around the gland to innervate it. In lab mice, researchers can separate the tiny embryonic nerves from the salivary gland by the 13th day after conception. For glands to grow and work properly, nerves are as essential as the blood vessels that supply oxygen and nutrients.

So that someday doctors will be able to repair or regenerate salivary glands, Matrix and Morphogenesis Section Chief and Senior Investigator Matthew P. Hoffman, B.D.S., Ph.D., has been identifying the cells, signaling pathways and other factors that are key for the gland's development and saliva-secreting function.

As the salivary gland develops in the embryo, the gland tissue and nerves communicate with each other. Using genetically modified mouse embryos to eavesdrop on the cross talk between the



tissues, Dr. Hoffman's team is identifying what drives the precise coordination. His goal is to isolate progenitor cells from a cancer survivor's body and transplant the cells inside the diseased salivary gland along with the factors they need to enhance or restore the ability to make saliva. Progenitor cells are precursor cells that have the potential to differentiate into many other cell types.

Dr. Hoffman and colleagues were the first to describe the cellular cross talk that promotes the development of nerves that wrap around the budding salivary gland. These findings are an important advance toward the goal of developing treatments that restore a cancer survivor's ability to make saliva. The researchers are learning how to coax the nerves of the salivary gland to communicate with the progenitor cells so that the newly regenerated tissue will secrete saliva.

Watching Nerves Develop

Dr. Hoffman's team is targeting a number of cell types, including K5+ (keratin-5-positive) progenitor cells, for potential use in salivary gland regeneration and repair. In adults, K5+ cells can be isolated from a patient's skin, salivary gland and other tissues.

In an embryo, the salivary gland needs a pool of K5+ cells in their precursor, undifferentiated state. If K5+ cells within the salivary gland all differentiate into other cells, the gland doesn't grow and develop properly. Six years ago, Dr. Hoffman's team published in the prestigious journal *Science* their discovery that nerve tissue maintains the K5+ cells within the gland in a precursor state. If the nerves are removed from an embryo, K5+ cells differentiate, the pool is depleted, and gland growth is impaired.

It has taken the work of many scientists over many years to get to this stage of research in Dr. Hoffman's lab. One of the NIDCR researchers, Wendy M. Knosp, Ph.D., was a postdoctoral fellow in Dr. Hoffman's lab at the time the most recent experiments were conducted. The project at NIDCR was a continuation of work she began at the University of California San Francisco (UCSF) in the lab of Gail R. Martin, Ph.D. Another researcher who played a key role in these studies, Sarah M. Knox, Ph.D., was a postdoctoral fellow in

Dr. Hoffman's lab at the time of the research and is now a UCSF assistant professor and continues investigations of gland development in her newly established lab.

Signals from the nerves maintain K5+ cells as precursor cells, and the K5+ cells produce the signals required for the initiation of innervation. In other words, the cellular cross talk in an embryo is bidirectional. The nerve cells help the salivary gland to develop its branched architecture by maintaining the K5+ cells as precursor cells, and the K5+ cells within the salivary gland help the nerve cells survive and innervate the gland.

Using molecular techniques and living tissue cultures from genetically modified mouse embryos, Dr. Knosp was able to determine that the signals coming from the K5+ cells were proteins called Wnts. Adding Wnt inhibitors to a culture of fetal salivary glands disrupts nerve development and branching. Usually, many of the nerve cells will wrap around the gland's duct, but when the research team added Wnt inhibitors, only some of the nerve cells wrapped around the duct.

Dr. Knosp's experiments were confirmed using genetically modified mice that did not have nerves around the salivary gland. By studying these mice, she discovered that the gland did not produce the Wnt signals that drive innervation of the salivary gland. As a result, the gland did not form properly.

By showing that Wnt signals are necessary for nerve development, the study provided a new mechanism for the regulation of innervation. With this new information, researchers may be one step closer toward the goal of developing methods of regenerating or repairing salivary glands for people with dry mouth.

Collaborating with Industry and Academia

To translate their findings into potential therapies, Dr. Hoffman's team is collaborating with researchers at Sangamo BioSciences, which is a biopharmaceutical company, and Michael Passineau, Ph.D., of the Allegheny-Singer Health Network. Their lab experiments with mini pigs are aimed at restoring salivary gland function. Because people and mini pigs have similar anatomy and saliva composition, and because they respond to radiation therapy in a similar way, mini pigs are a useful animal model for

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regenerating salivary glands.

Dr. Hoffman's research team is also collaborating with Robert Witt, M.D., FACS, and Swati Pradhan-Bhatt, Ph.D., of Christiana Care Health System and the University of Delaware to grow human salivary gland cells. They will isolate and expand the progenitor cell population needed to regenerate damaged salivary glands using a patient's own cells.

Summary

NIDCR conducts and supports a wide range of studies in the lab and clinic to improve the quality of life of people with oral, head and neck cancer. On the NIH campus in Bethesda, four NIDCR laboratories are working toward the research and development of methods that could alleviate the serious problem of dry mouth.

Editor's Note: Geriann Piazza, MA, is a writer/editor in the communications office of the National Institute of Dental and Craniofacial Research (NIDCR), a federal agency focused on research to improve the public's oral, dental, and craniofacial health. Geriann holds a bachelor of science in biology from Virginia Tech in Blacksburg and a master of arts in literature from the University of Houston-Clear Lake, and she studied epidemiology and public health at the University of Texas School of Public Health in Houston. NIDCR's free publications, such as the "Oral Health, Cancer Care, and You" series, are available at www.nidcr.nih.gov or by calling 1-866-232-4528. The NIDCR will continue to collaborate with SPOHNC and update us with vital information concerning oral, head and neck cancer.

Have an idea for a Feature Article topic?

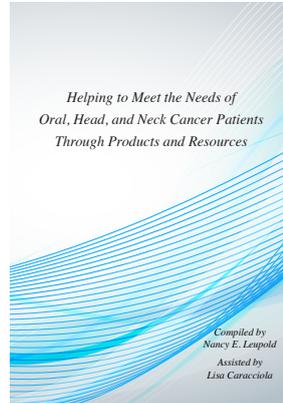


"News from SPOHNC" will be on its Summer hiatus following this issue, but if you have a topic you'd like to read about in the Fall, please e-mail us at info@spohnc.org and let us know.

We want to keep you informed!

SPOHNC's New Product Directory

"Helping to Meet the Needs of Oral, Head and Neck Cancer Patients Through Products and Resources" is now available. After many months of research, preparation and proofreading, SPOHNC's newest publication is available as a benefit of new membership. If you are a brand new member of SPOHNC, or if you renewed your membership or joined SPOHNC as a member on or after January 1st, 2016, you are entitled to this new book.



The side effects of treatment for oral, head and neck cancer can be debilitating, and long lasting as well. No other cancer

treatment leaves so many issues to deal with following treatment, into recovery and sometimes even beyond. Let SPOHNC help you to help yourself.

Full of product suggestions, the book addresses the side effects of treatment by offering more than 30 pages of products, information and resources. Everything from Radiation Dermatitis to Dental Issues and even Alternative and Complementary Therapies, is covered in this very thorough book. You will find product names, how and where to find them and a description of each product and how it can help. There's even a section in the back of the book for your own notes.

If you're not already a member of SPOHNC, become one today. Help support the programs and resources we offer, and gain important product knowledge to help you along your cancer journey and beyond.

To join SPOHNC, call us at 1-800-377-0928 or go to www.spohnc.org. Get your Product Directory today.

Survivor News



Recently, OncLive and Cure magazine published an inspiring piece, sharing the stories of three amazing and dedicated members of the

SPOHNC family. Maria Folchetti, of Howard Beach, NY, Dennis Staropoli of Sheffield, MA and Micki Naimoli of Philadelphia, PA were kind enough to share their very personal cancer journeys with OncLive and Cure.

To read their stories, go to www.spohnc.org or <http://www.curetoday.com/share-your-story/providing-a-dedicated-network-of-support-for-people-with-hnc>.

Thank you author Tony Hagen, for taking the time to listen to Maria, Dennis and Micki and for sharing their inspiring stories of hope and bravery.

Go Burgundy and Ivory

Add this to your casual Summer wardrobe



SPOHNC's newly designed

Oral, Head and Neck Cancer Awareness Wristband!

Purchase at a special discounted price of 5 for \$10.

These wristbands were created to raise awareness and show support to the thousands of patients, survivors, caregivers and healthcare professionals who have endured the journey of oral, head and neck cancer.

Call 1-800-377-0928 or go to www.spohnc.org to place your order.

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Time for Sharing...THE BIG "C" SCARE

'I CAN CURE YOU', those words made me draw hope. The diagnosis of stage four squamous cell carcinoma of the tonsil, metastasized to the lymph nodes were the first ones, and the latter was the response from Doctor Schmidt.



I recall the dreaded diagnosis and my own predictive prognosis. With so many unfinished deeds, so much financial concern and a profound "what about my wife, my family" dread, I slipped silently into a numb abyss. My only hope was that the team and the medicines could actually do what the doctor predicted. At fifty-five and reasonably healthy I would undergo something called "Neo Adjuvant Therapy" - basically a blitzkrieg of chemo, radiation and surgery.

"Schmitt" my affectionate avatar for my doctor, did say, and I quote "it will be like running a marathon." At first it will seem routine, but as we close for the finish it will drain all the energy from you and leave you asking whether you can finish the race. He was completely accurate.

The first round entailed large volumes of Cisplatin, Carboplatin and something called 5FU over three sessions. I always said the latter was the most aptly named chemo of them all. It did exactly as advertised.

Round one was okay, I had a few days of grief where I did not want to eat or drink but I survived and did the respite for round two. Dr. Demel, my oncologist, did say "this round will be more intense than the last." He of course was right as well. Eating became akin to tasting paper, and swallowing an exercise in choking. I made it through that round but contracted a mild pneumonia. They delayed the inevitable last round. With total hair loss, severe weight loss and neither an appetite for food nor water I staggered toward round three. Irritable, tired, rail thin and bald, I wondered whether I could complete my race.

A month of reprieve can revive like no other but then the radiation portion began. This time equipped with a feeding tube and a port for intravenous I was off once again to the races. The first step was a mask made to hold my head and neck steady during the directed photon energies. This claustrophobic experience is enhanced by a raised table and you inserted into a metallic donut for the energy beam. I counted the shots of energy by the audible beeps "168" per session for seven weeks with a good round of "jungle juice" every Monday. I coined that phrase to describe the Tamoxifen chemo that I received once per week, since it is derived from a rainforest botanical. Seven weeks later and fully 70 pounds lighter I could not screw in a light bulb. I remember Smitty saying at an après radiation appointment "Today I will just look at you. I'm afraid to touch you." My vulnerability must have been quite apparent.

I walked at my son's College graduation some eight days after radiation ended. The two weeks after the treatment's conclusion were the worst. Lean, weak, and barely recognizable to myself, I prodded toward the finish line. Radical neck surgery was scheduled for July and would reveal the results of the team's efforts. Surprisingly all the remnants of cancer were obliterated and I had a new lease on life. **Now nearly seven years has passed and I thank profusely the one person who inspired, healed, cared, and endured the most - my beautiful wife Patricia, without whom this story would have no author.**

Respectfully submitted with total empathy for all who have conquered those who are engaged in the battle with this insidious disease and my most heartfelt condolences to the many who fought the good fight but were overcome.

~ Ronald S. Bentley
ronaldsbentley@gmail.com

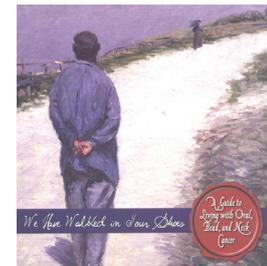
"I really like reading the stories and info from "News from SPOHNC..."

~ Harold L.



SPOHNC is seeking Sharing Stories for the upcoming issues of "News from SPOHNC." If you'd like to share the inspiring story of your cancer journey, contact SPOHNC at info@spohnc.org or call us at 1-800-377-0928.

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We Have Walked In Your Shoes: A Guide to Living With Oral, Head and Neck Cancer Second Edition

- Contains the basics about the symptoms and diagnosis of head and neck cancer, types of treatment and common side effects.
- Offers a section to list your healthcare team, a personal calendar and journal, diet and nutrition information, and a list of resources.
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"We Have Walked In Your Shoes" is a tremendous resource for OHNC patients."

~ Valerie T.

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Head and Neck Cancer News

Nivolumab New Care Option for Head and Neck Cancer

April 19, 2016 - Immunotherapy treatment with nivolumab significantly improved survival among patients with recurrent or metastatic head and neck squamous cell carcinoma (SCCHN), according to interim analysis results of the phase III CheckMate-141 study presented at the 2016 American Association for Cancer Research (AACR) Annual Meeting, held April 16–20 in New Orleans.

Patients in the study assigned to nivolumab had a 30% reduction in the risk for death, and in those patients who were PD-L1 positive and p16-positive—a marker for human papillomavirus positivity—the risk for death was reduced by approximately half.

“Nivolumab is the first agent to demonstrate a significant improvement in overall survival in patients with SCCHN who progress after platinum-based therapy in a randomized, phase III comparative trial and fulfills an incredible unmet need in the clinic,” said Maura L. Gillison, MD, PhD, a professor in the department of internal medicine at the Ohio State University Comprehensive Cancer Center in Columbus, Ohio. “Nivolumab, therefore, represents a

new standard of care option for patients with recurrent or metastatic SCCHN after platinum-based therapy.”

According to Gillison, about 50% of patients treated for SCCHN will have their disease recur within 3 to 5 years. SCCHN that recurs within 6 months is a particularly devastating disease with an average survival of less than 6 months, Gillison said.

The trial included 361 patients with SCCHN who had progressed within 6 months of receiving treatment with platinum-based chemotherapy. The patients were randomly assigned 2:1 to 3 mg/kg nivolumab every 2 weeks or weekly investigator’s choice consisting of single-agent chemotherapy with methotrexate, docetaxel, or cetuximab.

At the interim analysis, 55.4% of patients assigned nivolumab had died and 70.2% of patients assigned investigator’s choice had died. Patients assigned nivolumab had a 30% reduction in the risk for death compared with investigator’s choice (hazard ratio [HR], 0.70 [97.73% CI, 0.51-0.96]; $P = .010$). The median overall survival was more than 2 months longer for patients assigned the immunotherapy (7.5 vs 5.1 months; 95%

CI, 4.0–6.0).

Although nivolumab demonstrated a survival benefit in the overall study population regardless of PD-L1 expression or p16 status, the researchers also evaluated overall survival by these two factors.

Compared with investigator’s choice, nivolumab resulted in a 45% reduction in the risk for death (HR, 0.55) in patients with PD-L1 of 1% or greater and an 11% reduction in patients with PD-L1 less than 1%. Similarly, nivolumab was associated with a 44% reduction in the risk for death in patients who were p16-positive and a 27% reduction in the risk for death in patients who were p16-negative.

According to Gillison, the frequency, type, and grade of toxicity was similar to what was seen in other clinical trial populations. More than half of patients (58.9%) experienced treatment-related adverse events of any grade while on nivolumab and 13.1% had grade 3/4 events. However, in patients assigned to investigator’s choice chemotherapy, 77.5% experienced treatment-related adverse events and 35.1% had a grade 3/4 event.

###

There’s A Lot Happening!

SPOHNC continues to seek out new and unique opportunities for partnership and collaboration, raising awareness of oral, head and neck cancer and SPOHNC.

What’s New & Exciting?



SUPPORTING OUR TROOPS! - United States Military Medical Centers and several VA Medical Centers across the U.S. will be receiving copies of *We Have Walked In Your Shoes - A Guide To Living With Oral, Head and Neck Cancer, Second Edition*. *These books are being provided through the support of Lilly Oncology.*

*Each U.S. member of the American Head and Neck Society recently received a copy of **We Have Walked In Your Shoes - A Guide To Living With Oral, Head and Neck Cancer, Second Edition**. **These books were distributed with the compliments of EMD Serono USA.***

*We are happy to report that Walter Reed Army Medical Center is now offering **our first SPOHNC Chapter for active United States Military and beneficiaries.***



“As we express our gratitude, we must never forget that the highest appreciation is not to utter the words, but to live by them.”

John F. Kennedy

Austin Regional Clinic

Visit the SPOHNC website at www.spoHnc.org

HEAD AND NECK CANCER NEWS

Hepatitis C and Certain Head and Neck Cancers

People with hepatitis C may have at least twice the risk of developing certain head and neck cancers as individuals who don't carry the virus, a U.S. study suggests.

While the hepatitis C virus (HCV) has long been linked to other cancers, including tumors of the liver and blood malignancies known as non-Hodgkin lymphoma, the findings are among the first to link it to cancers in the head and neck, researchers note in the *Journal of the National Cancer Institute*.

"With new medications available, HCV is treatable and curable with more than 90 percent success rate," said senior study author Dr. Harrys Torres of the University of Texas MD Anderson Cancer Center in Houston.

"Thus, the first step is to screen and treat infected patients, because antiviral treatment can prevent some cancers (e.g. liver cancer and non-Hodgkin lymphoma) from ever developing," Torres added by email. "It remains to be shown whether curing the infection reduces the risk of head and neck cancers," he cautioned.

To explore the cancer risk associated with HCV infection, Torres and colleagues analyzed data on almost 35,000 patients at MD Anderson Cancer Center tested for the virus from 2004 to 2014, a group that included 409 people with head and neck malignancies.

Overall, 20 percent of the people with what's known as oropharyngeal cancers - tumors in the middle and back of the throat, tonsils, soft palate and back of the tongue - had HCV. So did 14 percent of people with non-oropharyngeal cancers - tumors of the front and underside of the tongue, roof of the mouth, larynx, gums and lips.

Because smoking is a major risk factor for head and neck cancers, researchers also looked at data for a control group of 694 people with lung tumors and other smoking-related malignancies. They found 6.5 percent of this control group had HCV.

Compared with patients in the control group, the researchers found the risk for HCV-infected patients of developing head and neck cancers was increased: 2.4 times higher for oral cavity cancers, 2 times greater for oropharynx cancers and almost 5 times for larynx cancers.

One limitation of the study is the lack of a control group of cancer-free patients, the authors note. The findings also don't prove that HCV directly causes head and neck tumors.

Hepatitis C is usually spread when blood from an infected person enters the body of someone who isn't infected. These days, most people infected with the virus get it from sharing needles or equipment to inject drugs, but it can also be transmitted during sex, and until a test for it was developed in

the early 1990s, people could acquire HCV through blood transfusions.

The Centers for Disease Control and Prevention recommends screening for people born during the "baby boom" generation from 1945 to 1965 and individuals with increased risk such those with AIDS or a history of drug use.

But a recent analysis of blood samples from nearly 5,000 emergency department patients seen at the Johns Hopkins Hospital in Baltimore found almost 14 percent tested positive for the virus - one third of whom didn't know they were infected.

If only people recommended for screening under the CDC guidelines got tested, 25 percent of the patients with undocumented hepatitis C wouldn't have been tested, that study found.

"The test is widely available and the consequences of not knowing your infection status can directly affect your health," said Dr. Thomas Quinn of Hopkins and the National Institute of Allergy and Infectious Diseases.

"Because hepatitis C virus can be cured, why not increase screening of the population and refer those that are positive to centers where they can be treated and thereby eliminate this associated risk for cancer," Quinn added by email.

###

Photo courtesy of PJ Jordan, NSVN Volunteer

Celebrate and Honor Those Who Care!



News from the U.S. Department of Health and Human Services, Health Resources and Services Administration - Each year from May 6 to May 12, we recognize the invaluable work of nurses during National Nurses Week. Nurses are the first line of defense in the prevention of illness and injury. They champion and promote the health of our nation. As healthcare leaders and trusted advisers on health issues, we

thank nurses for their continued efforts to improve patient outcomes in the ever-evolving field of primary care.

During your treatment and recovery, was there someone special who helped you along the way - taking special care to encourage you, make sure you were cared for in every way and who made you feel better each and every day of the long journey?

Celebrate that special nurse, clinician, friend, colleague, mentor or educator that has touched your life or has made a difference in the lives of others and the practice of nursing. Thank a special nurse today. Send your kudos to info@spohnc.org. We will feature your special nurse in a future issue of "News from SPOHNC"!



**HAPPY
MOTHERS DAY**

HEAD AND NECK CANCER NEWS

SPOHNC Collaborates for Oral, Head and Neck Cancer Awareness

THE WORD OF MOUTH ON ORAL, HEAD & NECK CANCER 2016

Diagnosis & Survival

600,000+
new cases
of oral cancer
each year worldwide

In the U.S., close to
48,330 individuals
will be diagnosed
with oral or
oropharyngeal
cancer this year

In the U.S. this year,
9,570 will die of oral
and oropharyngeal
cancers

MORE THAN 40%
of those diagnosed
with oral cancer die
within five years

Early diagnosis can
more than double
a patient's chances
of survival to **90%**

Risk Factors for Oral Cancer

What raises your risk?

 <p>VAPOR/ SMOKING/ SMOKELESS No amount is safe; risk increases with use</p>	 <p>ALCOHOL USE 14+ drinks/week for men; 7+ drinks/week for women</p>	 <p>EXPOSURE TO HPV (Human Papillomavirus 16)</p>	 <p>SMOKING + DRINKING People who both smoke and drink are at greatest risk</p>
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More Education & Prevention is Needed

 <p>58% of US consumers know little, or nothing at all about oral cancer</p>	 <p>65% of consumers are not aware that HPV is a risk factor for oral cancer</p>	 <p>ONLY 23% of consumers say their dental professional spoke with them about risk factors for oral cancer at their last dental appointment</p>
 <p>ONLY 37% of consumers reported being screened for oral cancer at their last dental appointment</p>	 <p>83% of respondents would like to be screened for oral cancer at every dental check up</p>	 <p>86% of consumers want their dentist to help them learn ways to reduce their risk of getting oral cancer</p>

SPOHNC recently partnered with Vigilant Biosciences, Inc. who create this infographic, designed to share information about a survey they conducted in the month of April. Vigilant Biosciences survey reflected results stating that among U.S. adults, the majority knows very little or nothing at all about oral cancer (58 percent) and only 37 percent reported being screened for oral cancer at their last dental check-up.

The survey found that the majority of consumers (86 percent) want to learn more about how to reduce their risk for oral cancer and are interested in simple screening tools, used in the dental office or at home, that test for early indicators of oral cancer and provide information on increased or decreased chance of developing oral cancer.

While just over a third of those surveyed recall being screened for oral cancer at their last dental check-up, a large majority would like to be screened at every check-up and would like their dental professional to use simple screening tools to assess their risk.



Your appeal envelope was included in your April newsletter.

The diagnosis of oral, head and neck cancer can be overwhelming. Remember to give hope.

Please support SPOHNC. Donate Today

Connect with SPOHNC's "group" on Facebook

Chapter News

Palm Coast, FL SPOHNC is Moving to Music Again!

As April Awareness Month came to a close, the national office of SPOHNC received some wonderful news from Amy and Lewis Beilman, Facilitators of the SPOHNC Palm Coast, FL Chapter. The 4th Annual Move to Music Exercise Class was a huge success!!!

While this comes as no surprise to SPOHNC, Amy and Lewis were very pleasantly surprised with the turnout of this year's event, held April 24th in the Grand Haven Clubhouse. Over 100 friends, neighbours, cancer survivors and family members came out to support the Beilman's efforts and join in this fun and exciting event. It was indeed a banner year



DRUM ROLL SOUND

for SPOHNC Palm Coast, FL – the Beilman's raised more than \$11,000 at Move to Music 2016!

The day began with a tremendous display of more than 65 amazing raffle prizes, donated by local community businesses, the sale of t-shirts and mini umbrellas, and a buzz of activity as Grand Haven geared up to begin the class with Lewis' custom music mix, beginning with American Authors "Best Day of My Life." What a fitting way to start the day!

Survivor, Lewis Beilman and his amazing Caregiver wife, Amy, are two of the most incredible people you could ever hope to meet. So grateful for the support of their good friends Sandi and Ron Walker, who found SPOHNC for them when Lewis

was going through treatment, the Beilman's made a pact to "give back" once Lewis was done with treatment. They have done so - willingly and enthusiastically, without ever looking back – since that very day.

SPOHNC is forever grateful to the Beilman's for their energy, ideas, inspiration and for the unwavering support they give to those who have become a part of their own Palm Coast, FL SPOHNC family.



SPOHNC Santa Maria, CA in The News!

SPOHNC Santa Maria, California will soon be celebrating its 7th Anniversary. In recognition of this occasion, the Chapter has made the local print media!

Chapter Facilitator, Aundie Werner, MS, CCC/SLP recently sent a lovely note to SPOHNC, along with a copy of the Santa Maria Times. In her note, Aundie expressed her appreciation for the opportunity to support head and neck cancer patients and survivors, saying "It is such a privilege to facilitate this wonderful group."

Everyone understands the importance of fitness, and keeping an active lifestyle. For cancer patients going through treatment and survivors who have completed their treatment, fitness is a way to reduce some of the side effects of treatment, while also reducing the risk of recurrence. It can increase stamina and produce endorphins, which help the body to recover faster from injury and illness. In one of two articles featured in the April 13th issue of the Santa Maria Times, Frank F., SPOHNC Santa Maria Chapter attendee, spoke of his experience and how his doctor recommended that he join the SPOHNC Chapter, for emotional support, and begin a fitness regimen through Mission Hope Cancer Center's rehab program – the

only program of its kind on the central Coast. With the help of a fitness trainer, Frank has been able to broaden his personal fitness expectations, while connecting with others who have had a similar experience. With his wife and caregiver by his side, he has been inspired to reach higher each time he attends a session. Frank is taking his life back, one workout at a time.

In the second feature story of the same issue, SPOHNC Santa Maria Chapter attendee Cynthia T. shared her story. Dealing with health issues of her young daughter, as all mothers do, Cynthia put her own health concerns on hold. A nagging sore throat was eventually diagnosed as stage three squamous cell carcinoma. Her treatment plan was immediately put into place and her physician recommended that she join the SPOHNC Santa Maria Chapter, where she would gain the support of others who had traveled a similar journey. Cynthia found others in the group with whom she could share her concerns and questions. She found camaraderie through being able to share her experience with others.

As someone with a lifelong love of singing, Cynthia was very worried about her ability to keep doing what she loved,

following her treatment. Would she be able to sing once again? She was not willing to give up her joy, and so enlisted the help of Aundie, who in addition to facilitating the SPOHNC Chapter, is a Speech Pathologist. Aundie became her greatest advocate and teacher, giving her the skills to relearn eating and swallowing, and thereby helping her to regain the ability to sing. Singing has been Cynthia's therapy, and she continues to improve each and every day, through exercises and methods that she works hard and continues to perfect. Cynthia can now sing again with her church choir, and she strives to hit every note, bringing joy to herself and others through her beautiful voice. Cynthia keeps a song in her heart each and every day!

Congratulations to Aundie, Frank, Cynthia and each and every SPOHNC Santa Maria, CA Chapter attendee on the celebration of 7 years of support, friendship and inspiration. SPOHNC is thrilled to share your inspiring stories of survivorship and hope and the joy you bring to yourselves and others each and every day, living your lives to your greatest potential and beyond! Best wishes for many more years of support and friendship.

Head and Neck Cancer News

Oncology Nurse-led Team Can Reduce Treatment Delays, Hospitalizations for Patients With Head and Neck Cancer

SAN ANTONIO, TX—An oncology nurse-led team approach can reduce treatment delays and hospitalizations and improve quality of care for patients with head and neck cancer, a program presented at the ONS 41st Annual Congress has shown.

Patients with head and neck malignancies often have complex psychosocial and medical issues; therefore, it is imperative that clinicians provide continuous evaluation and resources to this high-risk population.

In April 2014, oncology nurses at Steward Saint Anne's Regional Cancer Center in Fall River, Massachusetts, identified potential treatment-related sequelae that resulted in significant treatment delays when patients were receiving concomitant chemoradiotherapy.

"We found that our patients were not receiving proper education and care after treatment, because they were not being referred for speech and swallow, resulting in increased infection rates and hospitalizations," said Helena Viveiros, RN, BSN, OCN.

Their concerns were validated during a nursing-initiated 1.5 year review of their institution's morbidity and mortality records.

Specifically, they found that these issues result in a 59% risk of significant treatment delay with or without hospitalization.

Because previous research has demonstrated that nursing interventions can help minimize treatment delays and hospitalizations, oncology nurses at Saint Anne's created a multidisciplinary team that included social workers, dieticians, speech therapists, palliative care nurses, surgeons, radiation therapists, and the treating physicians, with the purpose of identifying interventions to limit treatment delays and interruptions.

The team developed and implemented an algorithm with the nursing staff in the surgery department to ensure timely referral to home care services for gastric tube management and early referral for swallow and speech therapy.

"Gastric tubes were put in by the surgeon, but there was no follow-up or just 1 teaching session for patients," Viveiros said. "We needed to support our patients better."

"We collaborated with the gastrointestinal physicians and home care services to provide aggressive supportive care," Viveiros said. Aggressive supportive care measures were

performed both during and after treatment.

Further, the team developed detailed educational materials for oral care and symptom management for distribution to patients and their caregivers.

They also established a protocol for biweekly oncology nursing visits during radiation to evaluate and quickly manage adverse events. If there were no adverse effects from treatment, the plan of care was continued; if adverse effects were present, the physician was notified and nursing interventions were initiated.

Following a 6-month review of 28 patients after implementing these interventions, the researchers found that hospitalizations and treatment delays were reduced by 34%. The team continues to meet monthly and performs chart reviews every 3 months to further improve this oncology nurse-led team approach.

"Oncology nurses can have a significant impact on patient outcomes, allowing patients to complete their prescribed course of treatment with minimal delay of treatment and hospitalization," Viveiros concluded.

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Eat Well Stay Nourished A Recipe and Resource Guide for Coping With Eating Challenges

\$20.00 includes shipping and handling.

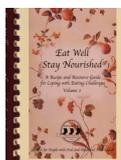
- Recipes & Information About Eating Challenges and Nutrition
- Cancer Journeys of Survivors
- Suggestions and "Tips from the Pros"



Eat Well Stay Nourished A Recipe and Resource Guide for Coping With Eating Challenges Volume 2

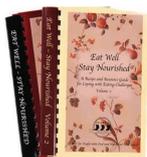
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- New Recipes
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Cool Off This Summer!

Try this recipe from
Eat Well Stay Nourished A Recipe and Resource Guide For Coping With Eating Challenges - Volume Two)

Pomegranate Smoothie

- 1 c. pomegranate or tart cherry juice
- 1 c. full fat plain yogurt
- 2 Tbsp. honey*
- ½ c. crushed ice



Combine all ingredients and mix in blender until smooth. Enjoy!

*Manuka honey has been shown to soothe mouth sores.

~ Hilary M, NY

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

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 and Summer fun!*



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