

# NEWS FROM S·P·O·H·N·C



VOL. 30 NO. 8

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

MAY/JUNE 2021



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

## Scientific Progress in Managing Treatment Side Effects for Head and Neck Cancer Survivors

Ron J. Karni, MD

Head and neck cancer patients are experiencing increasing rates of survivorship. This also means many patients are living with the side effects of head and neck cancer treatment. Common side effects I hear from patients include trouble swallowing, voice changes, airway edema (or swelling), neck swelling, muscular

scarring, stiffness and decreased range of motion – and none of these are fun. In my practice, we have put great emphasis not just on great cancer treatment, but on improving quality of life during survivorship.

Many of these common side effects can be traced to a condition called lymphedema. Lymphedema can be described as a traffic jam along the highway of lymphatic vessels.

Lymphatic vessels exist throughout the body and transport lymph fluid (containing immune molecules and other substances) towards the chest. When cancer infiltrates a lymph node or when a node is removed during surgery, lymphatic flow is interrupted, which can start a cycle of swelling and inflammation.

I wrote an article about lymphedema for SPOHNC back in 2013. At that time, we knew that head and neck lymphedema (HNL) with its associated functional losses affected as many as 75% of head and neck cancer (HNC) survivors 3 months or more after HNC treatment<sup>1</sup>. However, we didn't know a lot about why

this was happening or how best to treat it. Over the past few years, many physicians including myself conducted studies to understand more. First, how is the treatment of head and neck cancer impacting the onset and progression of lymphedema? Second, what treatments are effective in treating patients' lymphedema symptoms?

In answering the first question, we conducted trials using infrared imaging to see how lymph fluid moved during various stages of cancer treatment. What we learned was that mild lymphedema may be present before treatment, at the time of head and neck cancer diagnosis.<sup>2</sup> Cases of lymphedema increased after radiation therapy; in fact, most patients develop moderate to severe lymphedema after radiation. Early lymphedema causes feelings of tightness, heaviness, or soft swelling, and problems swallowing. Left untreated, tissues become hard and fibrotic which is difficult to treat and it can cause new or worsening symptoms<sup>3</sup>. Thus, aggressive and early treatment of lymphedema is critical for the best long-term patient outcomes.

This led to our second question: What are effective treatments for lymphedema? A commonly recommended treatment for lymphedema is complete decongestive therapy by a therapist including patient education, manual lymphatic drainage, compression garments, exercise, and skin care. Most HNC patients undergo brief professional therapy followed by a lifetime of daily home self-care. While this approach may prove effective for some patients, lymphedema fails to respond adequately in others<sup>4-8</sup>. Many other patients experience barriers to access this lymphedema care in the first place including cost or insurance obstacles, lack of certified and experienced lymphedema therapists nearby, and self-limitations (e.g., physical or cognitive impairments). Thus, cost effective, home based treatment options for both primary and refractory lymphedema remains an unmet need.

Although widely used for breast cancer patients with lymphedema, a self-treatment tool that hadn't yet been studied extensively in head and neck patients was an advanced pneumatic compression device (APCD). An APCD includes an electric air pump and a garment that attaches to it via simple air hoses. The pump inflates the garment providing a gentle, directional massage similar to what a therapist would perform or teach a patient to perform at home. An APCD automates this therapy for more consistent results, making it easy to use for daily home management of symptoms.

In the case of the head and neck, the APCD has two garment pieces; one that fits over the head and another worn as a vest. The vest garment chambers inflate in the chest area first, moving the lymph fluid and creating a pathway for the fluid in the head/neck to move to. Secondly, the head garment chambers inflate and push the lymph fluid downward into the chest.

A team of clinicians at Vanderbilt University conducted a study of 43 patients to determine how typical home management

LYMPHEDEMA continued on page 2

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Chris Leonardis

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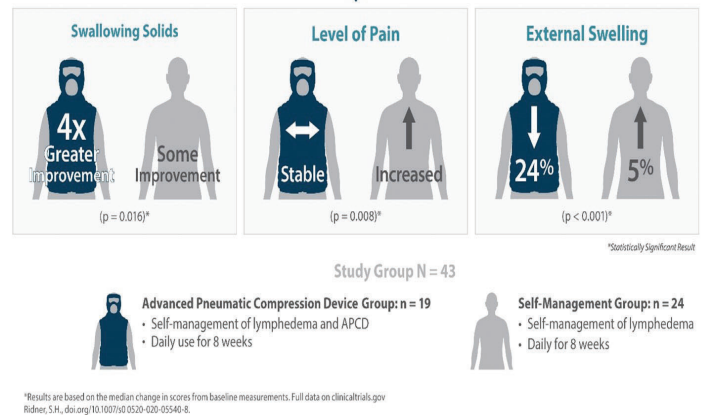
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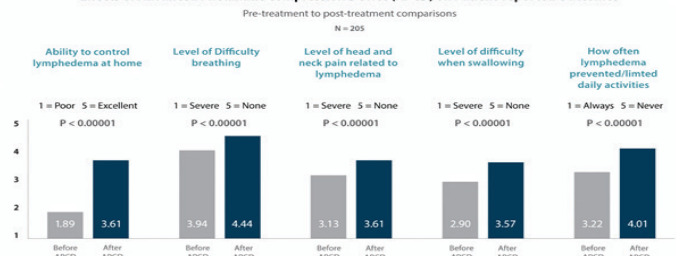
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would compare to an APCD<sup>9</sup>. Patients were randomized to either the “usual care” group or the “APCD group.” The patients’ symptoms were measured via clinically validated patient surveys and objective measurements before and after their respective treatments. The results showed statistically significant improvements in symptoms for the patients that used APCD. The most impactful improvements were shown in swallowing solids, reduction in swelling, and stabilized level of pain. Additional improvements were found in mucous related symptoms, the severity of soft tissue related symptoms, and neurological symptoms. This study was published in May of 2020 in the Journal for Supportive Care in Cancer and you can read the full study here: <https://doi.org/10.1007/s00520-020-05540-6>

**Advanced Pneumatic Compression (APCD) vs. Self-Management Alone:**

The results described in the 43 patient Vanderbilt study were also seen in a study of a much larger group of 205 patients. A colleague of mine, Dr. Carolina Gutierrez, analyzed the patients’ reported symptoms from before and after they received their Advanced Pneumatic Compression Device. The patients reported on 5 symptoms: 1) Ability to control lymphedema at home, 2) Level of difficulty breathing, 3) Level of head and neck pain related to lymphedema, 4) Level of difficulty when swallowing, and 5) How often lymphedema prevented/limited them from their daily activities. In each of these questions, patients had statistically significant improvements after they used the APCD for 90 days than before they had received it. This study was published in March 2020 in the Journal of the Sciences and Specialties of the Head and Neck and you can read the full study here: <https://onlinelibrary.wiley.com/doi/10.1002/hed.26110>

**Effects of Advanced Pneumatic Compression Device (APCD) on Patient-reported Outcomes**

LYMPHEDEMA continued on page 3

LYMPHEDEMA continued from page 2

On the surgery side of things, I am continuing to research and learn how best to minimize the effects of cancer treatment while still completely removing the cancer. On the survivorship side, we continue to work on how best to treat the patients' symptoms. Research from Dr. Sheila Ridner shows that 90% of head and neck cancer survivors will suffer from lymphedema 1 year out from their treatment<sup>1</sup>. New therapies like pneumatic compression for self-management can be very impactful for survivor quality of life, especially today when COVID-19 adds to existing access barriers to professional therapy. If you are suffering from the symptoms of lymphedema, tell your doctor. The earlier you receive treatment the better off you will be.

*Patient Experience Report:*

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*Editors Note: Ron J. Karni, MD serves as Chief of the Division of Head and Neck Surgical Oncology in the Department of Otorhinolaryngology–Head & Neck Surgery at UT Health. He obtained his medical degree at Baylor College of Medicine and then completed his residency training at Washington University in St. Louis School of Medicine. Dr. Karni has authored publications on the novel treatment of occult primary oropharyngeal cancer (the unknown primary) and practical tools to integrate evidence-based methods into the daily practice of medicine. His current research focus includes de-escalation treatment strategies for throat cancer, morphoproteomic analysis of head and neck cancer, and HPV-related malignancies of the head and neck. He is also co-Principal Investigator on a CPRIT grant studying new treatments for head and neck lymphedema using near infrared fluorescent technology. Dr. Karni is board certified by the American Board of Otolaryngology–Head & Neck Surgery.*

*“Keep up  
the  
good work”*

*~ Ben N.*

*“Listening to Spring”*

How quietly the earth breathes forth new life. How eagerly the sun bleeds for the spring,

*I am listening.*

I am listening to seeds breaking open, to roots growing strong beneath the ground, to green shoots rising up from the winter wombs.

I am listening to thorns blossoming, to barren branches laughing out new growth, to wildflowers dancing through the meadows.

*I am listening.*

I am listening to the forest filling up with song. I am listening to the earth filling up with life. I am listening to trees filling up with leaves.

*I am listening.*

I am listening to the sky with its many changing moods, to flashes of lightning, peals of thunder, to opening buds and greening grass....

I am listening to the breaking form of light in the vestibule of dawn. I am listening to the freshness of the morning.

*I am listening.*

I am listening to the brook, to the song of happy waters. I am listening to music rising up from all the earth. I am listening to spring soaring on wings of life. I am listening to the sounds of spring.

I am listening to prayers pouring forth from feathered throats. I am listening to prayers rising up from misty waters. I am listening to prayers of a meadow crowned with dawn.

*I am listening.*

I am listening to the growing in the garden of my heart. I am listening to my heart singing songs of resurrection. I am listening to the colors of life.

*I am listening.*

I am listening to winter handing over spring. I am listening to the poetry of spring.

*I am listening.*

\*From “Listening to Spring” (excerpts) From The Circle of Life, by Macrina Wiederkehr



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## IMPORTANT NEWS FROM SPOHNC

*Upcoming Webinar August 19th at 10:00 am EST*

### *Learn How to Make an Impact on Xerostomia (Dry Mouth) Treatments*

On August 19th, in collaboration with Support for People with Oral and Head and Neck Cancer (SPOHNC), the Head and Neck Cancer Alliance (HNCA), the National Foundation

of Swallowing Disorders (NFOSD) and the THANC (Thyroid, Head and Neck Cancer) Foundation will be hosting an Externally-Led Patient-Focused Drug Development (EL-PFDD) meeting on a topic which has affected many patients and survivors. EL-PFDD meetings give the FDA and other key stakeholders, including medical product developers, health care providers, and federal partners, an important



opportunity to hear directly from people living with xerostomia, their families, caregivers, and patient advocates about the symptoms

that matter most to them, the impact the disease has on people's daily lives, and their experiences with currently available treatments. This input can help inform the FDA's decisions and oversight during drug development and new drug review, which is crucial for expanding options for improving

the lives of those living with xerostomia.

Patient Focused Drug Development meetings are a way to hear from and learn from patients and families about what it is like to live with xerostomia. This information will eventually be used when new treatments are being developed to treat xerostomia.

No one understands what it is like to live with xerostomia except you! Please join us on August 19th and learn how your voice can contribute to this discussion.

Please check your email frequently for news from SPOHNC about how to join this webinar. We look forward to hearing from you!

### Don't Miss Any News!



*If you have moved, or changed your email address or phone number, be sure to contact SPOHNC at 1-800-377-0928, or email us at [info@spohnc.org](mailto:info@spohnc.org) to let us know.*



## Choosing Safer Activities

	Unvaccinated People	Your Activity	Fully Vaccinated People
		Outdoor	
Safest		Walk, run, or bike outdoors with members of your household	
		Attend a small, outdoor gathering with fully vaccinated family and friends	
		Attend a small, outdoor gathering with fully vaccinated and unvaccinated people	
Less Safe		Dine at an outdoor restaurant with friends from multiple households	
Least Safe		Attend a crowded, outdoor event, like a live performance, parade, or sports event	



*photo courtesy of PJ Jordan, SPOHNC NSVN Caregiver Volunteer*

***Eat Well Stay Nourished  
A Recipe  
and Resource Guide  
for Coping  
With Eating Challenges***  
compiled by  
*Nancy E. Leupold, Founder;  
in memoriam*



*SPOHNC is offering  
a great bargain for its  
Eat Well Stay Nourished  
Vol. One and Vol. Two  
Cookbooks...  
Buy One Get One (BOGO).*

**BUY ONE  
GET ONE**

*Both cookbooks help to prepare  
recipes for those who are coping  
with eating challenges.*

***For a limited time SPOHNC  
is offering a discounted price  
of \$25.00 (includes shipping &  
handling) for both Volume One  
and Volume Two...a \$15.00  
savings.***

*Purchase a gift set for your loved one  
or friend who you know is struggling  
with their daily meal plans for  
nutrition.*

*Go to [spohnc.org](http://spohnc.org) to order  
or call SPOHNC today  
at 1-800-377-0928*

**Yummy Summer Recipes 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*

***Pomegranate Smoothie - from Volume Two***

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

\*Manuka honey has been shown to soothe mouth sores. Available online or in health food stores and supermarkets.



Combine all ingredients and mix in blender until smooth. Enjoy! 1 serving/430 calories per serving.

~ Hillary M., NY



***Tarragon Zucchini Egg Dish - from Volume One***

- 2 lb. zucchini
- 4 eggs
- 1/3 c. sour cream
- 1 tsp. tarragon leaves, chopped
- 2 mint leaves (optional)
- 1 Tbsp. butter
- 2 Tbsp. olive oil
- 1 egg yolk
- Salt and pepper to taste



Cut the zucchini the long way into strips, then steam until soft, about 10 minutes. Saute them lightly in the oil and butter for 3 to 5 minutes, turning on all sides. Puree the zucchini in the food processor. Add eggs and beat. Add sour cream, mint (optional) and tarragon. Season with salt and pepper. Place mixture in buttered Pyrex baking dish. Bake 20 minutes at 350 degrees. Cool. Serves 4 to 8/238 calories per serving.

~ Pat C., MN



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## IMPORTANT NEWS FROM MEDICARE

### *Medicare Savings Programs*

You can get help from your state paying your Medicare premiums. In some cases, Medicare Savings Programs may also pay Medicare Part A (Hospital Insurance) and Medicare Part B (Medical Insurance) deductibles, coinsurance, and copayments if you meet certain conditions. These conditions are listed below under “How do I apply for Medicare Savings Programs?”

#### *4 Kinds of Medicare Savings Programs*

If you have income from working, you still may qualify for these 4 programs even if your income is higher than the income limits listed for each program.

- Qualified Medicare Beneficiary (QMB) Program
- Specified Low-Income Medicare Beneficiary (SLMB) Program
- Qualifying Individual (QI) Program
- Qualified Disabled and Working Individuals (QDWI) Program

If you qualify for the QMB program, SLMB, or QI program, you automatically qualify to get Extra Help paying for Medicare drug coverage.

#### *Note:*

These amounts may increase each year. If your income and resources are slightly higher, you should still apply.

#### *What items are included in the Medicare Savings Program resource limits?*

##### Countable resources include:

- Money in a checking or savings account
- Stocks
- Bonds

##### Countable resources don't include:

- Your home
- One car
- Burial plot

- Up to \$1,500 for burial expenses if you have put that money aside
- Furniture
- Other household and personal items

#### *How do I apply for Medicare Savings Programs?*

If you answer yes to these 3 questions, call your State Medicaid Program to see if you qualify for a Medicare Savings Program in your state:

- Do you have, or are you eligible for, Part A?
- Is your income for 2021 at, or below, the income limits listed for any of the programs above?
- Do you have limited resources, below the limits above?

It's important to call or fill out an application if you think you could qualify for savings—even if your income or resources are higher than the amounts listed here.

*For more information go to [medicare.gov](https://www.medicare.gov)*

## SPOHNC National Survivor Volunteer Network (NSVN)

### *WE KNOW WHAT YOU ARE GOING THROUGH!*

SPOHNC “National Survivor Volunteer Network” has been serving patients and their caregivers since 2004, bringing them the opportunity to share diagnosis and treatment experiences with someone who has “walked in their shoes.” This unique matching service pairs volunteers who have gone through diagnosis, treatment, and recovery with patients or family members who are just beginning their journey, or are now recovering from the side effects of treatment. Patients and volunteers are matched by diagnosis and treatment plan. Volunteer survivors offer valuable insight, information, support, hope and encouragement.

Many people feel a desire to “give back” after reaching survivor status. The NSVN network is always looking for additional volunteers.

If you are a survivor of head and neck cancer, or a caregiver, you know the importance of reliable information, and gaining strength from the support and encouragement of those who “walked in your shoes.”

If you, or your caregiver

- Have the desire to help others
- Have good listening skills

...then, we encourage you to contact SPOHNC by phone at 1-800-377-0928, or by email at [info@spohnc.org](mailto:info@spohnc.org) to join our volunteer network.

Please consider contributing your personal insight by volunteering to help others in need, because

### *Together We Heal*

WE LOOK FORWARD TO HEARING FROM YOU!



*photo courtesy of PJ Jordan - NSVN caregiver volunteer & awesome photographer!*

#### **Did You Know?**

**SPOHNC**  
has matched more than 1,300  
patients and survivors  
through the  
National Survivor  
Volunteer Network  
matching program?

**Visit the SPOHNC website at [www.spohnc.org](https://www.spohnc.org)**

## CHAPTER NEWS

*What a Beautiful Day!!*

*News from the SPOHNC Syosset, NY Chapter*

Covid has made the past year seem like the longest ever. Cancelled vacations and holidays, grocery shopping online and just staying home became the norm. While it was nice to be at home for a while, we are all yearning for a little something different. With each state's guidelines in mind, our SPOHNC Chapter support groups are looking toward the future to see what they may

be able to plan, for meetings, events and other happenings. Our "home group" in Syosset, New York, decided it was time to make the move.

On Sunday, May 23<sup>rd</sup>, here on Long Island, the sun was shining, the birds were singing, and the SPOHNC Syosset, NY Chapter support group did something they haven't been able to do in a long time...they got together – in person!

Frank Marcovitz is the Co-Facilitator of the Syosset, NY SPOHNC Chapter, which has been conducting its monthly meetings remotely for over a year. While these meetings have been highly successful, there has been a yearning to see each other in person, a desire shared by many during these pandemic restricted times. At the suggestion of one of the group's newest members, Frank organized a picnic at a beautiful local park. In attendance were several members, spouses, children and grandchildren. The group was excited to also welcome SPOHNC's Executive Director, Mary Ann Caputo, and her husband, Larry, to the event!

Everyone brought some food to share. This was a chance to get together socially,



share stories, have some laughs and soak up the wonderful weather. The children played ball, threw frisbees, and one boy even went horseback riding at the stable next to the park. Everyone was so pleased to be

able to enjoy the event, and the group looks forward to having some more such events in the future.

Frank said... "We had a great time!! So nice seeing everyone in person and enjoying each other's company in a beautiful setting."

Group attendee Chavon G. was so excited to be there with her family...she exclaimed to SPOHNC – "Our journey, our time! We are all at different stages...we have

made it! Bravo, job well done!"

Brian and Donna McMahon were there too – and Brian said "It was nice to get out and see the group!"

SPOHNC Executive Director commented... "the day couldn't have been more beautiful...it was a magnificent day... it was a GIFT! Seeing all the faces of our SPOHNC family and their loved ones was truly an amazing sight, after being quarantined and only

seeing one another virtually for many, many months. It was such a wonderful feeling of joy to see all the caring and love amongst one another. Everyone enjoyed each other's company while delighting in the dishes shared by all. Kudos to Frank Marcovitz, SPOHNC's Syosset, NY Co-Facilitator for putting this picnic together. He is our "Ironman" who has gone through his own difficulties with this disease.

SPOHNC is grateful to our SPOHNC Syosset Facilitators, Frank, and Alice Steiner, and all of our volunteers who go the extra mile to connect with patients, survivors and their families to ensure each one knows they are not alone in their cancer journey."

**Send Us  
Your Chapter News!**

**HAVE you GOT NEWS FOR us?**

*Especially as things begin to open back up - if you do something special with your Chapter, share it with us, so we can share it with our readers.*

*We all need happy news!!*



## HEAD AND NECK CANCER NEWS

### *Tislelizumab Combination Met Primary End Point for First-Line Treatment of Nasopharyngeal Cancer*

May 21, 2021 - Matthew Fowler

BeiGene's press release details the positive progression-free survival data observed with the combination of tislelizumab plus chemotherapy compared with placebo plus chemotherapy for patients with recurrent or metastatic nasopharyngeal cancer.

Tislelizumab plus chemotherapy met its primary end point of progression-free survival (PFS) at the interim analysis of the phase 3 RATIONALE 309 trial (NCT03924986) investigating the combination as first-line treatment for patients with recurrent or metastatic nasopharyngeal cancer, according to a BeiGene, Ltd. press release.<sup>1</sup>

The randomized, double-blind, placebo-controlled trial evaluated the safety and efficacy of tislelizumab plus gemcitabine and cisplatin compared with placebo plus gemcitabine and cisplatin for this cohort of patients.

"We are excited to see a clinically meaningful improvement in progression-free survival in our Phase 3 trial for tislelizumab plus chemotherapy in patients with [nasopharyngeal cancer]. This is our fifth positive phase 3 readout for

tislelizumab, which we are developing broadly as a potentially differentiated anti-PD-1 antibody," Yong Ben, MD, Chief Medical Officer, Immuno-Oncology, at BeiGene, said in a press release.

The trial enrolled 263 Asian patients and randomized them 1:1 to receive either tislelizumab or placebo plus chemotherapy. The results showed a statistically significant improvement in PFS for the intention-to-treat (ITT) population treated with tislelizumab plus chemotherapy compared with the placebo plus chemotherapy group. PFS was evaluated by an independent review committee (IRC).

No new safety signals were detected with the anti-PD-1 antibody when chemotherapy was added, as the safety profile was consistent with the previously known risks of the drug.

Secondary end points of the trial including overall survival, objective response rate assessed by IRC, duration of response, and investigator-assessed PFS.

According to the press release, BeiGene expects to present the data at an upcoming medical conference and is also discussing the results with health authorities.

"We are grateful for the patients and clinicians who participated in this trial and hopeful that they may have a new treatment option in the future," explained Ben.

BeiGene, the biopharmaceutical company responsible for tislelizumab, previously announced preliminary phase 2 data at the 2019 American Society of Clinical Oncology (ASCO) Annual Meeting. The research team investigated drug as monotherapy in Chinese patients with nasopharyngeal cancer.<sup>2</sup>

A total of 20 patients were enrolled in the trial and treated with a dose of tislelizumab at 200 mg every 3 weeks. At the data cut-off point, the median treatment duration was 7.5 months (range, 2.1-15.8 months) with a median follow-up time of 11.7 months.

The most common treatment-related adverse events in this study were hypothyroidism (24%), anemia (14%), increased AST (10%), and hemoptysis (10%).

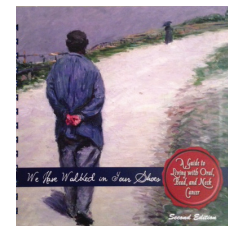
According to the release, tislelizumab is a "humanized IgG4 anti-PD-1 monoclonal antibody specifically designed to minimize binding to FcγR on macrophages."

## SPOHNC Resources

SPOHNC's most popular resource for newly diagnosed patients is now available as a Digital Edition!

### *We Have Walked In Your Shoes: A Guide to Living With Oral, Head and Neck Cancer -*

by Nancy E. Leupold &  
James J. Sciubba, DMD, PhD



### **DIGITAL EDITION Available NOW!**

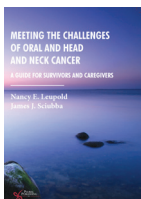
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### *Meeting the Challenges of Oral and Head and Neck Cancer A Guide for Survivors and Caregivers - Second Edition*

by Nancy E. Leupold &  
James J. Sciubba, DMD, PhD



Learn about Treatment Options,  
Nutrition, Quality of Life, Pain,  
Oral Care, Insurance Issues

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## A Time for Sharing...Steve's Journey

For years I experienced sore throat, nasal congestion and relentless post nasal drip. Over those years I did frequent my doctor. She felt that I suffered from allergies and instructed me to use an over the counter nasal spray. My condition seemed to worsen with the addition of an earache in my right ear. In August 2019 I found a new doctor. He told me to continue what I was doing and to contact him if things did not improve. In a couple of months I got back to him and he put in an order for me to get an ultra sound on my neck. This was the first step on my cancer journey.

So the progression started. Shortly after I got my first C-scan and found my current Ear Nose and Throat doctor. He said that he needed to do a biopsy to determine what the tumor was. It was either caused from alcohol and tobacco or the HPV virus. The biopsy revealed HPV and carcinoma on the base of the tongue and right tonsil. At that time he explained that I would be receiving 35 treatments of radiation therapy and 7 weekly sessions of chemotherapy. He also told to see my dentist in case I needed to get teeth pulled, see an audiologist to determine any hearing loss from the chemotherapy

and finally meet with a speech pathologist to work on swallowing since that might be affected from the chemotherapy. I was overwhelmed.

At that time I was teaching 4 yoga classes a week. For over nine years previous I taught 10 to 15 yoga classes per week. Prior to that I was a corporate cafe food service director and a chef before that. For over twenty years I have had a personal yoga and meditation practice which I feel helped me navigate this journey.



The practice of yoga is really about understanding and using your breath. The use of the breath can help the to calm the mind in addition to managing the sympathetic and parasympathetic nervous systems. The practice also helps the 9 systems of the body including: skeletal, muscular, digestive, endocrine systems.

I began my radiation treatments in August 2019. While on the radiation table I asked them to turn off the music and used what is called Ujjai breath. This is where you breath through the nose only. This was at times helpful since you have a "popsicle" in your mouth. I also occupied by mind with meditative techniques like "the breath in time" where you pick a number and count backwards each time you take an inhalation and exhalation. I also counted mala beads.

I was able to continue teaching into the 4th week of my treatment. At that time my muscular body has lost too much strength so I also gave up my practice. Worse than that was my inability to speak to my family. Combined with the mucous and mouth sores I was unable to eat or consume liquid. Mornings were especially difficult for me since I attempted to clear the mucous out of my mouth and throat area leaving me gagging. By the time the radiation was finished I had lost 40 pounds but now I continue to slowly regain weight.

While going through these treatments I continued to look for anything to allow for a better experience. Six weeks ago I started live video on Facebook named Yoga4throatcancer. My Facebook page is Harmony Thai Yoga Studio. The sessions are about fifteen minutes long at 9:30am Monday and will remain for a while. They include easy yoga movement, breathe work and meditation. The idea is to provide something to use or more importantly to create strategies to help with those on this journey. There is no charge and you can feel free to contact me.

I wrote this a few weeks after my treatment ended:

*This is the Body I got  
This is the Body I work with  
This is the Body I grow*

~ Steve Retzlaff  
retzlaff.pam@icloud.com

## Your Cancer Story

### Supporting the Cancer Community

This #NationalCancerSurvivorMonth, we reflect on the additional challenges the #cancer community has faced over the past year. We're proud to partner with @Merck to deliver resources through Your Cancer Story to help those living with cancer. #MerckPartner

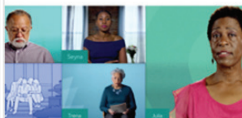
In 2021, there will be approximately 1.9 million #cancer cases diagnosed. We're proud to partner with @Merck to share helpful resources for this growing community.



Sharing stories from those who have lived through it



and who can offer you support every day.



Discover resources for:

- Communication
- Physical Health
- Emotional Health
- Survivorship



### Share Your Journey in "News from SPOHNC"

SHINE YOUR LIGHT.  
share YOUR JOURNEY.

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authors.*

**Connect with Newsletter Editor,  
Chris Leonardis at 1-800-377-0928,  
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## HEAD AND NECK CANCER NEWS

### *Researchers Uncover Protein That Helps Tumors Evade System*

June 3, 2021- Different types of immunotherapy work in different ways. Some immunotherapy treatments help the immune system stop or slow the growth of cancer cells. Others help the immune system destroy cancer cells or stop the cancer from spreading to other parts of the body. A new mouse study by researchers at the Francis Crick Institute demonstrates a potential new immunotherapy target. The researchers uncovered a protein that aids tumors evade the immune system.

Their findings are published in the journal *Cell* in a paper titled, "Secreted gelsolin inhibits DNGR-1-dependent cross-presentation and cancer immunity."

"Cross-presentation of antigens from dead tumor cells by type 1 conventional dendritic cells (cDC1s) is thought to underlie priming of anticancer CD8+ T cells. cDC1 express high levels of DNGR-1 (a.k.a. CLEC9A), a receptor that binds to F-actin exposed by dead cell debris and promotes cross-presentation of associated antigens. Here, we show that secreted gelsolin (sGSN), an extracellular protein, decreases DNGR-1 binding to F-actin and cross-presentation of dead cell-associated antigens by cDC1s," the authors wrote.

The scientists identified secreted gelsolin, a protein that is present in blood plasma and is also secreted by cancer cells, and discovered how it interferes with the immune system's defenses by blocking a receptor inside dendritic cells.

Clinical data and samples from cancer patients with 10 different types of the disease were analyzed, and the researchers observed that individuals with liver, head and neck, and stomach cancers, who have lower levels of this protein in their tumors had higher chances of survival.

The researchers also discovered that blocking the action of secreted gelsolin in mice with cancer increased their response to treatments including checkpoint inhibitors.

"The interaction between tumor cells, the surrounding environment, and the immune system is a complex picture," explained Caetano Reis e Sousa, PhD, group leader of the immunobiology laboratory at the Crick and one of the study's authors. "And although immunotherapies have revolutionized the way certain cancers are treated, there's still a lot to understand about who is most likely to benefit.

"It's exciting to find a previously unknown mechanism for how our body

recognizes and tackles tumors. This opens new avenues for developing drugs that increase the number of patients with different types of cancer who might benefit from innovative immunotherapies."

The researchers observed that secreted gelsolin outcompetes a key dendritic cell receptor, blocking its ability to bind to F-actin and therefore the ability of the dendritic cells to initiate a T-cell response.

"Dendritic cells play a vital role in the immune system and our body's response to cancer," says Evangelos Giampazolias, PhD, author and postdoc in the immunobiology laboratory at the Crick. "Understanding this process in more detail will enable us to identify how cancers are able to hide and how we might remove their disguise."

"Our results reveal a natural barrier to cross-presentation of cancer antigens that dampens anti-tumor CD8+ T cell responses," wrote the researchers.

The team is hopeful they can develop a potential therapy that targets the secreted gelsolin in the tumor without affecting the activity of this protein in other parts of the body. Their findings may pave the way for other strategies and treatments that target this protein.

## HEAD AND NECK CANCER NEWS

### *Your Covid-19 Vaccination Card - Answers to Common Questions*

*Medically Reviewed by UPMC -  
May 13, 2021*

#### **What Should I Do With It?**

Keep your card in a safe place at home after receiving all doses of your vaccine. You can store it in a safe place with your social security card, birth certificate, and other important papers. If you have a passport, it fits nicely inside the passport for safe storage.

If you took a photo of it, make sure you can access the photo from different places. If the photo is only stored on your phone and you lose your phone, you lose the copy. You also can make photocopies of the card to store in a safe place.

Do not post your card on social media or any other public site. It contains personal information that scammers can use for identity theft. It also could provide

information for people making fake cards.

Bring your card with you the next time you see your primary care provider or other regular doctors. Those providers can enter the information into your medical record.

Some people may want to laminate their card. However, if booster shots become necessary, providers may want to record the boosters on the same card. Laminating the card could make it harder to record additional shots.

#### **What Happens If I Lose My Vaccine Card?**

It's a good idea to take a photo of your card in case you lose it. If you lose the card before your appointment for your second dose, you can get other proof of your first shot. The Centers for Disease Control and Prevention recommends these steps:

- Contact the vaccination site where

you received the vaccine to ask for a replacement. If you received your doses at different vaccine sites, experts recommend contacting the site of the second dose.

- If you cannot contact the provider who gave you the vaccine, call the state health department's immunization information system (IIS). The contact information for each IIS is here. Vaccine sites report COVID-19 vaccinations to the state's IIS.
- If you enrolled in V-safe or VaxText after your first dose, you can visit the website to look up your vaccine information.
- If you cannot get a copy of your vaccine information, go to your scheduled appointment and ask for help.



# CHAPTERS OF SPOHNC

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

PLEASE NOTE: 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 to find out more information.

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the good work  
of SPOHNC."***

*~ Barbara S.*

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