

# SPOHNC

SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER | EST. 1991



## Penn State Hershey Holds a Garden Party

On Wednesday evening, August 23rd, the Penn State Hershey Chapter of SPOHNC held its 9th Annual Summer Garden Party at the home of survivor Karen Rhoad and her husband, Steve. The couple have graciously opened their home to the group every year for this special get-together.

A gathering of survivors and exceptional caretakers attended, three of whom were wives of brave warriors who finally lost their battle but will always be remembered...

As always, it was a lovely occasion filled with warm camaraderie and tasty dishes, creating lasting memories!

## September Champion of Hope

A champion for many!  
Turn to page 7.

## What I Did On My Summer Vacation!

Read all about it on page 8.

## Massachusetts Patients & Survivors Needed!

Find out more on page 9.

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## Nerve Problems or Peripheral Neuropathy

ASCO and Cancer.net

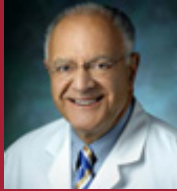
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*SPOHNC is dedicated to raising awareness and meeting the needs of oral and head and neck cancer patients through its resources and publications.*

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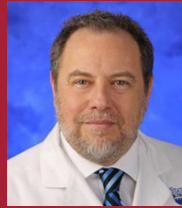
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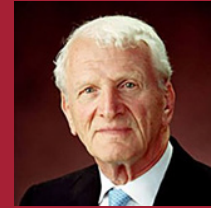
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Chris Leonardis

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# Nerve Problems or Peripheral Neuropathy

Nerves are bundles of fibers in the body that help you sense, feel, and move. The nervous system is the name of the network that the nerves form.

There are 2 parts to the nervous system: the central nervous system and the peripheral nervous system. The central nervous system is made up of the brain and spinal cord, a thick cord of nerves inside the spine. All other nerves in the body are a part of the peripheral nervous system. Peripheral nerves send information between your brain and your body.

Nerve problems are called neuropathy. Damage to your nerves in the peripheral nervous system is called peripheral neuropathy. Neuropathy can cause problems related to sensing, feeling, and moving. The specific problems depend on which nerves are affected.

Cancer and cancer treatment can cause peripheral neuropathy. Treating and relieving side effects is an important part of cancer care and treatment. This is called palliative and supportive care. Talk with your health care team about any symptoms you have, including new symptoms or changes in your symptoms.

What are the symptoms of neuropathy?

Nerve problems are different for every person. The symptoms you experience and how serious they are depend on which nerves are damaged and how many are damaged.

There are 3 types of nerves that send messages to your brain and spinal cord: sensory nerves, motor nerves, and autonomic nerves. Symptoms will depend on the type of nerve that is affected.

**Sensory nerves.** These nerves affect your sense of feeling. Damage to sensory nerves can cause:

- Tingling, burning, buzzing, or numbness
- Pain that can feel like pinching, sharp stabs, burning, or electric shocks
- Tightness
- Discomfort that gets worse when you touch something
- Difficulty feeling hot and cold or knowing if you hurt yourself
- Problems knowing where your hands

and feet are in space, causing difficulty walking or picking things up

**Motor nerves.** These nerves send information between your brain and muscles. Damage to motor nerves can cause:

- Problems walking or moving
- Legs or arms that feel heavy or weak
- Balance and coordination problems
- Difficulty using your hands and arms, making everyday activities like texting or buttoning a shirt a challenge
- Muscle cramps

**Autonomic nerves.** These nerves control the body functions you do not have to think about. Damage to autonomic nerves can cause:

- Being unable to sweat normally
- Digestive problems, such as diarrhea and constipation
- Dizziness or lightheadedness
- Trouble swallowing
- Urinary problems
- Problems with sexual health

Talk to your health care team if you have any of these problems or notice changes in problems you have had for a while. If nerve problems worsen, your health care team may adjust your treatment.

Can chemotherapy damage nerves?

Some types of chemotherapy drugs can cause neuropathy. When chemotherapy causes neuropathy, it is called “chemotherapy-induced peripheral neuropathy” or CIPN. These drugs include:

- Bortezomib (Velcade)
- Platinum-based chemotherapy, including cisplatin (Platinol), oxaliplatin (Eloxatin), and carboplatin (Paraplatin)
- Taxanes, including docetaxel (Docefrez and Taxotere) and paclitaxel (Taxol)
- Thalidomide (Synovir, Thalomid)
- Vinca alkaloids, including vincristine (Vincasar), vinorelbine (Navelbine), and vinblastine (Velban)

Before cancer treatment begins, ask your doctor if any of the drugs in your treatment plan can cause damage to the nerves. They can tell you your risk for developing neuropathy after receiving chemotherapy. This is an especially important step for people who already have neuropathy or who have conditions that may put them at greater risk of developing neuropathy, such as diabetes or a family history of nerve problems. See below for more examples of conditions other than cancer that can cause neuropathy.

Always talk with your doctor before taking any supplement or over-the-counter medication, because they can interact with cancer treatments.

Other cancer-related causes of neuropathy  
Other types of cancer treatment and cancer itself can damage nerves and cause neuropathy. Other cancer-related causes of neuropathy include:

**Where a tumor is located.** A tumor might press on or grow into a nerve. This can cause nerve damage.

**Radiation therapy.** Nerve damage caused by radiation therapy can begin quickly and get better, but most radiation-induced peripheral neuropathy takes months or years to cause problems and can worsen over time.

**Surgery.** Cuts made during surgery can damage nerves and cause neuropathy.

**Cancer-related health problems.** Sometimes, your immune system reacts to healthy cells instead of cancer cells. This is called a paraneoplastic disorder. When the immune system reacts to nerve cells instead of cancer cells, it can cause nerve problems.

What other conditions can cause neuropathy?

Sometimes, a condition other than cancer causes nerve problems. Or nerve problems you had before you developed cancer can be made worse by cancer and cancer treatment. Other conditions that can cause neuropathy include:

- Diabetes
- Drinking too much alcohol
- HIV, the virus that causes AIDS
- Autoimmune diseases, such as lupus or rheumatoid arthritis (RA)
- Thyroid problems, especially low thyroid hormone levels, which is called hypothyroidism
- Kidney problems
- Certain inherited conditions that affect nerves

- Lead poisoning or being exposed to pesticides

If you have had nerve problems in the past or if you have any of the conditions listed above, tell your doctor before cancer treatment begins. Learn more about managing your care when cancer is not your only health concern.

How is neuropathy treated?

The right treatment for nerve problems depends on the cause, whether chemotherapy treatment is finished, and your specific symptoms. Nerve problems often go away a few months or years after treatment. But sometimes, they are long-lasting or permanent. Your health care team can help you find the best ways to cope with your neuropathy.



Managing side effects such as nerve problems is an important part of cancer care during and after treatment, called survivorship or follow-up care. Talk with your health care team about any symptoms or side effects you or the person you are caring for experience.

Treatments and strategies for coping with neuropathy include:

**Medication.** There are medications to relieve the pain from neuropathy. But pain medications do not relieve numbness related to neuropathy. Your doctor might first recommend non-prescription medication, called over the counter medication, if the pain is mild. These include pills that can be taken by mouth and creams you put on the skin, depending on the type of nerve problem.

There are also prescription medications that can help. You may also be prescribed anti-inflammatory drugs or painkillers. Prescription medications can include pills you take by mouth and creams or patches you put on the skin, such as a lidocaine patch.

**Adjusting your chemotherapy treatment plan.** If you develop neuropathy from ongoing chemotherapy that causes severe pain or affects your ability to function, your health care team may adjust your chemotherapy treatment plan. This could mean giving chemotherapy doses further apart, lowering the amount of chemotherapy you receive, or changing the treatment plan in other ways.

**Exercise.** Exercise can help you cope with neuropathy by reducing pain and improving balance. However, the symptoms of nerve damage can make exercise challenging.

**Physical therapy.** A physical therapist or cancer rehabilitation specialist can help you learn movements and balance exercises to help cope with nerve problems. These specialists may also help you use devices that stimulate the skin with electricity, including scrambler therapy and a transcutaneous electrical nerve stimulation (TENS) device. Cryotherapy, also called cold therapy, may also be an option. More research is needed into these techniques, but they might help. Always talk to your doctor, physical therapist, or cancer rehabilitation specialist before you start an exercise program or buy any devices to help with nerve problems.

**Occupational therapy.** You can also work with an occupational therapist. This type of therapist helps you find ways to safely do daily activities, even with nerve problems. This might include using specific devices, such as a long pole to pick up items on the floor if balance is a problem. Or, it could include helping you adjust your home to reduce your risk of falling. Learn more below about how to stay safe at home when you have neuropathy.

**Nutrition.** Eating a diet that includes specific nutrients may help some types of nerve problems. For example, there may be a need more B vitamins, including B1, B12, and folic acid (folate), or more antioxidants. These are found in many fruits and vegetables.

Ask your doctor how much alcohol is safe to drink, if any. Also ask your doctor or other health care team members about eating a balanced diet. A registered dietitian nutritionist (RD/RDN) can help to make sure what you eat and drink is helping your nerve problems and not making them worse.

**Acupuncture/acupressure.** Acupuncture can be used for many different problems, including neuropathy. This form of Traditional Chinese Medicine involves inserting special needles into the specific parts of the body. Acupressure and reflexology are practices similar to acupuncture, but during these practices, the specialist uses their hands instead of needles to apply pressure to specific points on the body.

Ask your health care team for recommendations about practices and providers. If you are receiving acupuncture, make sure to see an experienced practitioner who only uses sterile needles and preferably has experience working with people with cancer.

**Other treatments.** These integrative/complementary therapies might help reduce pain caused by neuropathy and mental stress:

- Massage
- Relaxation and mindfulness meditation

### **How to stay safe if you have neuropathy**

Having nerve problems raises your risk of hurting yourself, especially at home. These tips can help you avoid getting hurt.

#### **Prevent falls**

- Keep all rooms, hallways, and stairways well lit.
- Put handrails on both sides of the stairway.
- Remove things you could slip or trip on, such as loose rugs or clutter.
- Put grab bars and hand grips in the shower, tub, and next to the toilet.
- Stick rubber mats in the tub or shower so you do not slip.
- Ask your doctor if a cane or walker would help.

#### **Prevent burns or other injuries**

- Check the temperature of your hot water at home. Set your hot water heater's top temperature under 110 degrees Fahrenheit/43 degrees Celsius to prevent burns.
- Clean up spilled liquids right away.
- Use dishes that do not break easily.
- Wear rubber gloves when you wash dishes for a better grip.
- Use pot holders when you cook to protect your hands.

#### **Other ways to help**

- Check how well you can feel the pedals and steering wheel of your car. Can you switch your foot quickly from the gas to the brake? If not, ask someone else to drive and let your doctor know.
- Put cushioning mats in your home and work areas to make standing more comfortable.
- Wear shoes with rocker soles. These are also called "rocker-bottom" soles. Many of these look like regular shoes, including fashionable ones. They can help you stay safe and comfortable.

Consider asking your health care team these questions about neuropathy:

- Does my cancer or cancer treatment put me at risk for developing neuropathy?
- Is neuropathy a common side effect of the chemotherapy treatment I will receive?
- What signs of neuropathy should I watch for? Which ones should I tell you about right away?
- Can you recommend a physical therapist, rehabilitation specialist, or occupational therapist who can help me manage neuropathy?
- Can you recommend trained providers, such as an oncology dietitian, acupuncturist, or massage therapist, who can help me manage the symptoms of neuropathy?
- How can I make my home safer if I am having trouble walking or with my balance?
- Why is it important to protect my skin from burns and injury? What are ways to do this?
- Could regular exercise help with my neuropathy?
- What exercises are safe for me to do?

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## Autumn Sweet Potato Smoothie

Wendy M. - Ohio  
Volume 2, pg. 25

### Ingredients

- 1 1/3 c. (200 g) red grapes
- 1/2 medium orange, peeled
- 1/2 (5 oz.) sweet potato, cooked & cooled
- 1/2 (4.1 oz.) medium apple, halved
- 1/4 c. (25 g) fresh or frozen cranberries
- 1/2 tsp. fresh ginger or ginger paste
- 2 dates, pitted
- 2 c. (480 ml) ice cubes



### Directions

- Place all ingredients into the Vitamix container in the order listed and secure lid. Select Variable 1. Turn machine on & slowly increase speed to Variable 10, then to high. Blend for 1 minute, using the tamper to press the ingredients into the blades. Serves 2.

### Nutritional Information Per Serving:

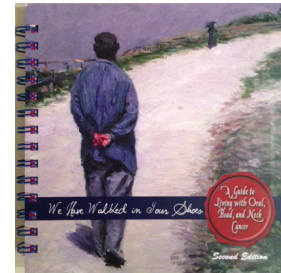
- Calories 100, Protein 1 (g), Carbohydrate 25 (g), Dietary Fiber 3 (g), Total Fat 0, Saturated fat 0 (g), Cholesterol 0 (mg), Sodium 25 (mg).

## SPOHNC's RESOURCES

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

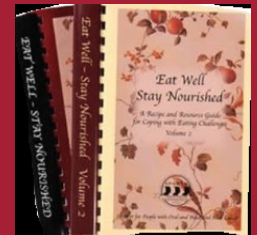


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# September Champion of Hope

## Valerie Goldstein - SPOHNC Boston, MA Chapter Facilitator

SPOHNC's September Champion of Hope is one of our very favorite people. Valerie Goldstein has been part of our SPOHNC family since she became a member in 2000, after her diagnosis and treatment in 1998. She came to SPOHNC for support, and never looked back. Valerie is a lovely woman. She is supportive, inspiring, knowledgeable, capable and always willing to help with whatever, and however, she can. She is a career woman, animal lover and a very dedicated volunteer.

Valerie has been the Facilitator of the Boston, Massachusetts SPOHNC Chapter for almost 23 years. The group had previously met at Massachusetts General Hospital, and then another location, until the pandemic. Valerie took it all in stride and pulled the group back together, and they held their first Zoom support group meeting on July 9, 2020. The support group continues to Zoom today. Like several other groups across the country, it's working well for them!

SPOHNC staff and a special guest of honor attended their Zoom 20<sup>th</sup> Anniversary Celebration in November of 2020. Dr. Eugene Myers is a distinguished member of SPOHNC's Board of Directors, and was more than happy to celebrate with the group. Dr. Myers gave a very comprehensive presentation about head and neck cancers and treatment options and was very welcoming when it came to questions from the group. He answered many inquiries and made the group feel very much at ease throughout his presentation. He was grateful to be invited to connect with this special group of patients and survivors.

Valerie also joined our National Survivor Volunteer Network (NSVN) matching program as a volunteer in 2003. Since that time, she has supported more than a dozen newly diagnosed patients along their cancer journey. Valerie



has served as the Co-Chair of the Massachusetts Oncology Patients Survivors and Supporters (MOPSS) committee for the past 2 years. House Bill 1094 is a crucial piece of legislation addressing dental and quality of life issues faced by head and neck cancer survivors in Massachusetts. This bill will require insurers doing business in the state to cover medically related dental treatment. This effort is gaining ground as the committee makes plans to present their personal stories in the coming Fall government sessions, to various committees at the State House. Valerie is spearheading bi-weekly meetings while keeping supporting documents in an organized packet, and continues to be a driving force of the committee along with Chairperson and fellow survivors, Tom Healy and Amy Gross.

In the past, Valerie also attended SPOHNC's 20<sup>th</sup> Anniversary and Celebration of Life which was held in New York. The weekend celebration included guest speakers, inspirational stories and a chance to network and enjoy social time with fellow patients and survivors. It was a wonderful get-together, and we hope to put together another event in the coming years. As a survivor, Valerie enjoyed the weekend events and had the chance to connect with others who were traveling their cancer journey.

Valerie continues to support SPOHNC through all of our endeavors, helping our programs to grow and flourish along the way. She continues to be a force with the MOPSS Committee, and a helping hand and a listening ear for patients, survivors and caregivers alike. She supports her SPOHNC Chapter support group, and those we match her with through our matching program and is always glad to be of help in any way she can.

Valerie, we are honored to call you our September Champion of Hope. We extend our heartfelt gratitude to you for all that you continue to do for fellow survivors, each and every day.

Thank you so much for your dedication and unwavering support, always.

"I really appreciate  
all that you do"

~ Mark D. Kilmartin

# Survivor News

## What I Did on my Summer Vacation!

Ah Summer... The time to relax and recharge, and maybe go on an adventure? That's just what some of our SPOHNC family members have done this year, so we thought we would share their adventures with you. Take a look, enjoy and maybe you can plan an adventure of your own!

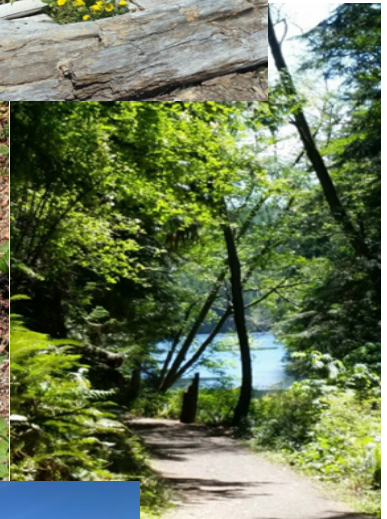
"Almost six years after my diagnosis and I am enjoying my trip to the Netherlands."

~ Ken Solomon



"We are both working for Denali Air. I'm flying and Connie is working the front desk and picking up passengers. The picture is of our plane that I flew up from PA. We are having a blast!"

~ Chris & Connie Lunt



Survivor, Kathleen Godwin and her husband Joe are spending the Summer in their RV in Anacortes, Washington.

Kathleen shared some great photos of a beckoning path, in one of the last old growth forests in Washington state, a screech owl, the beach and some really big trees!!



Survivor, Jane Sittambalam sent along some great photos from a recent trip. She went to Iceland, Norway, Amsterdam and Belgium and ended up in England. It was a family trip to celebrate her husband's upcoming 80th birthday and his brother's 75th. Such beautiful scenery!



Thanks to all for sharing your Summer adventures with SPOHNC!!



# Calling All Massachusetts Head and Neck Cancer Survivors!



**The MOPSS Committee has been working diligently toward this goal for several years and THEY NEED YOUR HELP!**

If you live in Massachusetts, please contact your state representative or state senator to ask for their support for Bill H.1094 and/or contact [mopssma@gmail.com](mailto:mopssma@gmail.com), 617-444-9045 to let us know you have reached out.

**If you live in Massachusetts** and would like to join the MOPSS Committee, they are actively seeking more committee members so that their voices will be heard! Please contact Tom Healy or Amy Gross at [mopssma@gmail.com](mailto:mopssma@gmail.com) or by phone at 617-444-9045 for details about upcoming meetings and how you can participate.

## Massachusetts Oncology Patients, Survivors, and Supporters (MOPSS) Update

**Massachusetts Bill H.1094: An Act expanding coverage of dental procedures related to or resulting from a medical condition for which coverage is provided.**

*Massachusetts Oncology Patients, Survivors, and Supporters (MOPSS)* is working with elected representatives in Massachusetts on Bill H.1094. If passed, this Act would require all insurers doing business in Massachusetts to cover medically-related dental treatment.

This effort is actively endorsed and supported by SPOHNC and its Massachusetts chapter support groups, as well as Dana-Farber Cancer Institute, Mass General Brigham, the Massachusetts Society of Otolaryngology/Head and Neck Surgery, Inc., the Massachusetts Society of Clinical Oncologists, Mass Eye & Ear, UMass Memorial Health, MGH Division of Dentistry, Ryan S. Lee, DDS, MPH, MHA, FAGD, FICOI, Cape Cod Healthcare, Southcoast Health, MGH Danvers and Beth Israel Lahey Health. The list of supporters, institutions and organizations continues to grow as MOPSS outreach continues!

*Like, follow and share MOPSS' new LinkedIn ([MOPSS LinkedIn](#)) and Facebook ([MOPSS FaceBook](#)) pages! Or you can find MOPSS by searching Massachusetts Oncology Patients, Survivors and Supporters on the web!*

If this bill passes in Massachusetts, it can be the model program for other states to follow. Let's make MA Bill H.1094 happen!! "Ain't no stopping us now!" Get on the MOPSS bus!!!!!!

**Dental care is health care and all Massachusetts residents deserve it! Support MA Bill H.1094!!!!!!**

**"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!"**

# My Story -

Brian S. Foley, MD, MBA

First off, I'm sending you a virtual high-five, and boy, does your journey deserve a standing ovation! My story strikes a parallel chord, so allow me to share, and I hope you find some comfort and kinship in it. In 2001, I, too, was blindsided with a head and neck cancer diagnosis at the ripe age of 34. Like you, I faced this monstrous hurdle with determination. I had a fighting spirit and an unflinching belief that I would come out on the other side stronger than ever.

## My Long History

The next couple of years were a roller coaster ride. I got multiple opinions and considered many treatments. I opted for a simple surgical resection. In some ways, I became a nicer, healthier, and more mindful person after that. But, of course, I lived in fear of a recurrence. I had a few areas of leukoplakia and dysplasia but did very well for years.

Later, a biopsy revealed a

squamous cell carcinoma on my tongue in 2005, requiring yet another surgery. After what felt like a tumultuous journey, life was beginning to normalize. I again stayed positive and functioned well for many years with close surveillance.

Eventually, I stumbled upon a new painful lesion in 2021. We hoped it wasn't cancer-related. The continuous discomfort and subsequent examinations confirmed the inevitable - cancer was back. A major surgery involving skin grafts and a stay in the ICU was the only viable solution. Post-surgery rehab came with physical therapy, occupational therapy, and speech therapy. They helped and allowed me to return to work.



The pain worsened. Further scans exposed an aggressive malignant tumor, warranting more surgery. That was followed by low-dose chemotherapy and 33 radiation sessions in 2023.

Despite the destructive power of radiation and chemotherapy, I emerged victorious against cancer. However, this victory came with its price. Osteoradionecrosis, a complication from radiation, made its painful presence known. Yet another surgery was needed to resect part of my mandible and to biopsy the floor of the mouth.

I manage osteonecrosis with pain medication, antibiotics, and hyperbaric oxygen treatments. The journey has been long, daunting, and trying at the best of times, but as I look back, I'm thankful. Thankful to be alive, functioning, and able to share this story more than 20 years after my original diagnosis.

Life is strange. It throws curveballs at us, some that seem too massive to dodge. But I've learned that we are stronger than we realize. Each scar, each wound, and each hurdle faced is a testament to our resilience. Kintsugi. Look it up!

## Lessons Learned

### This Cancer is Nasty

It can be aggressive and relentless. Each recurrence seems closer together and worse. It started on my superficial tongue. Now it has involved the base of my tongue, the floor of my mouth, and inside my jaw. The stage of the disease keeps going up with each recurrence.

### Early Treatment is Key

I attribute my 20 years of success to excellent care with vigilant observations and follow-up. We prefer biopsy and/or advanced imaging if there is any suspicion of a new lesion. Early excision and biopsies have saved my life.

### Prevention May Help

It is hard to judge the effectiveness of this one. I made changes after my original diagnosis. My health became a higher priority. I started exercising regularly. I stopped drinking alcohol and switched to green tea. I flood my diet with as many antioxidants as possible. We stock black raspberry juice/berries, turmeric, garlic, coffee, avocado, and green leafy vegetables. How much did all this help me survive for more than two decades? That can't be proven one way or the other. But most of the changes are enjoyable and help for other reasons.

## **Expect an Emotional Rollercoaster**

This whirlpool of an experience reshaped my understanding of life. One crucial lesson I've learned is that emotions are powerful, and harnessing them can be a significant part of healing. Fear, frustration, hope, despair - they're all part of the journey. Acknowledging my emotions, instead of denying them, helped me better navigate this tumultuous time. It was okay to be scared and yet hold onto hope.

## **Expect Side Effects**

The side effects of pain medications were a tough pill to swallow, both literally and figuratively. There was constipation, drowsiness, and on some bad days, nausea. But the alternative - dealing with pain without these meds - was an even harder battle. Finding the right balance and communicating with my doctor was essential. It allowed us to find the right meds and doses that helped manage the pain without compromising too much of my quality of life.

Although the radiation helped beat cancer, it brought along complications like osteoradionecrosis. It was a sharp reminder that every solution might have its own challenges. Navigating this obstacle taught me never to underestimate my inner strength and that it's okay to rely on others when things get tough.

## **Listen to Your Pain & Instincts**

Talking about hope and disappointment, they walked hand in hand throughout my journey. The biggest disappointment? Discovering the aggressive malignant tumor after briefly returning to work. I tried to grin and bear it and ignore it for a while. But inevitably, I needed it addressed. It felt like I had been sucker-punched just as I was beginning to regain my footing. Yet, hope never really left my side. It found its way into my heart every time I made small progress, like when the cancer was destroyed following chemotherapy and radiation.

## **The Importance of Imaging**

There were several times when my surgeon thought everything looked good, but they didn't feel good to me. Whenever possible, I erred

on the side of getting additional imaging. In my experience, MRI, X-rays, and CT-PET all show different views of the same tissue. There have been times when one seemed suspicious of malignancy, and the others didn't. If you don't agree with your doctor, get a second opinion.

## **Disability Insurance is Critical**

As for the experience with disability insurance, it was a lifesaver, a beacon of financial stability in a sea of medical expenses. My employer hasn't paid me in nearly a year. The process of claiming insurance was daunting at times, but it was worth the effort. It reinforced my belief in planning for uncertainties and underscored the importance of a good safety net.

I have a disability policy through my work. The short-term portion worked well by maintaining my normal paycheck for the first thirteen weeks. After that, it became a long-term claim. That required applying all over. The LTD (long-term disability) policy paid less than my paycheck. It also pays for only two years. Fortunately, I have two other private disability policies that I have carried and paid for over the last 25+ years. I qualified for payment from all three LTD policies, which has helped with expenses.

## **Avoiding My Pity Party**

I sometimes think or feel, "Woe is me." Or ask, "Why is this happening to me?" "What did I do to deserve this." Fortunately, I can usually pull myself out of that useless funk. I remind myself that I can't control what happens to me. I don't always understand why things happen in life. My role is to control how I respond and to do so in a positive way. Better questions to ask myself are: "How can I make something good out of this?" "What about this experience can I use to make me a better person."

## **Ask For Help**

It is not only okay but necessary to ask for help. My social support played a key role in every aspect. I'm fortunate to have a dedicated, involved spouse who helped with every step. We also allowed friends and relatives to make meals, give gifts, watch our children, and drive me to radiation treatments. If you believe in a higher power, ask Him for help too.

My cancer journey was an emotional rollercoaster. It taught me resilience, the power of hope, and the importance of preparing for life's curveballs. But most importantly, it taught me to value life and the beauty of everyday moments.

Keep the faith, my friend. We are survivors, after all.

~ Brian Foley, MD

[dr\\_foley@yahoo.com](mailto:dr_foley@yahoo.com)

# How Can I Help?

Did you have someone to talk to along your cancer journey who understood what you were going through?



SPOHNC's National Survivor Volunteer Network provides newly diagnosed patients, and their caregivers with someone who understands... someone who has been there.

Are you looking for a way to give back after your cancer journey? Consider joining SPOHNC as a volunteer for our National Survivor Volunteer Network. If you are a survivor, or a caregiver to a survivor who is out of treatment for at least a year, contact SPOHNC at **1-800-377-0928**, or **email us at [info@spohnc.org](mailto:info@spohnc.org)** to find out how you can help.

# Share Your Story

SPOHNC's **Time for Sharing** is looking for your story. Would you care to share your cancer journey, so you can give hope to someone just beginning theirs?

Sharing your story is one of the most powerful ways for a newly diagnosed patient to know they are not alone. Email us at [info@spohnc.org](mailto:info@spohnc.org) to find out more. We look forward to hearing from you soon!



# Head and Neck Cancer Research Project

**SHARE YOUR PERSPECTIVE ON LIVING WITH HEAD AND NECK CANCER AND EARN \$200**

IQVIA™ ([www.iqvia.com](http://www.iqvia.com)), a healthcare research firm, is currently conducting a research project with patients 18 years of age or older, who have been diagnosed with advanced or metastatic head and neck cancer by their physician. The research will involve participating in two telephone interviews. Each of these interviews will last for approximately 60 minutes. In appreciation of your time, IQVIA is offering an electronic gift card voucher of \$200.

The research will focus on understanding your experience with head and neck cancer, as well as assess questionnaires designed to evaluate treatment benefits in a clinical trial. This research may help improve how the patient experience is accounted for in future clinical trials.

***The study is strictly for research purposes; there will be absolutely no sales or promotional activities.***

Share your experience living with Head and Neck Cancer

IQVIA

IQVIA wants to understand the experiences of patients living with locally advanced, locally metastatic or metastatic head and neck cancer through two compensated 60-minute telephone interviews

SCAN HERE TO SEE IF YOU QUALIFY

# In Memoriam - Bill Pennington

It is with deepest sympathy that SPOHNC shares news of the passing of Bill Pennington, who was an active participant in the Dallas Fort Worth, Texas area SPOHNC Chapter support groups for more than 15 years.

Bill was born, along with his twin sister, Suzanne Marie, on March 28, 1947, in Chicago, Illinois. He grew up in Lombard, IL. He graduated from Yale University, and also earned a Master of Business degree from the University of Chicago. During his time at Yale, he met the love of his life, Karen.



Bill began a long career in the telecommunications industry upon graduation. His focus was both local and international, always part of the innovation and implementation of the most current telecommunication technology.

As a huge sports fan, Bill loved his Dallas and Chicago sports teams, and Formula 1 Racing

as well. He loved watching his sons, and more recently, his grandchildren, play competitive sports.

Bill truly had a selfless heart, always giving his time to support others. He was a family man, loved to travel, and dabbled in scuba diving. He will be remembered for his Christian values, Trivial Pursuit expertise, his photographic memory, his interest in military history, World War II documentaries, his love of action movies, and his patriotism. He was very proud his eldest son and grandson, who currently serve in the United States Navy.

Jack Mitchell, SPOHNC Dallas Fort Worth, Texas area Chapter Facilitator, and a good friend of Bill's, shared these words with SPOHNC:

“Bill had attended the Dallas Fort Worth area SPOHNC Support Team Meetings for 15 years, some months attending all four monthly meetings. Bill was my ‘Go To Guy’ when I needed someone to facilitate a meeting when I could not attend. Over the years, Bill helped and supported many survivors with their cancer journey. Quick with a smile or a positive comment, Bill will be missed. Our thoughts and prayers go out to Bill’s wife, Karen, and his three sons and their families.”

Our SPOHNC family echoes Jack’s sentiments, and we will keep the Pennington family in our prayers. Rest in Peace, Bill.

## Medicare.gov

It’s easier to stay up to date with your immunizations now that **people with Medicare Part D pay nothing out of pocket for even more vaccines.** This means more people with Medicare can get protection against disease and severe illness.

**Medicare Part D now covers these vaccines and more at no cost to you:**

- Shingles
- RSV
- Tetanus/diphtheria (Td)
- Tetanus, diphtheria, and pertussis (whooping cough) (Tdap)
- Hepatitis A
- Hepatitis B, if you’re at low risk for the virus

Also, Medicare still covers flu shots, COVID-19 vaccines, and pneumococcal shots.

Stay up to date with vaccines. Talk with your doctor about which vaccines are right for you!



# Head and Neck Cancer News

*SPOHNC periodically assists companies with studies where patients, survivors, and even caregivers can provide information, and be compensated for their time. If you're on social media, or if you receive SPOHNC's eblasts, you may have seen this study before.*

There is a study opportunity available for oral head and neck cancer survivors or caregivers. Compensation for this study is \$500 for 120 minutes.

If you have any questions about the study, please email - [ihaveavoice@dscience.com](mailto:ihaveavoice@dscience.com).

“Your magazine does it all.”

**Your voice matters.**  
**Are you a survivor or caregiver of oral head and neck cancer?**

Participate in our upcoming feedback and usability study for a new medical device related to oral medication.

**Advocate for your healthcare.**

Study Dates	<b>Summer and Fall 2023</b>
Locations	Philadelphia, Chicago, and around the US!
Compensation	<b>\$500 for 120 minutes</b>

@designscience  
[dscience.com/signup](https://dscience.com/signup)

**Questions?**  
Email - [ihaveavoice@dscience.com](mailto:ihaveavoice@dscience.com)

## Head and Neck Cancer News

### *High oral HPV burden puts older men at risk of oropharyngeal cancer*

Dr. BiCuspid - Aug 22, 2023 - Oral HPV burden is highest among older men, which puts them at higher risk of developing oropharyngeal cancer, according to research published in JAMA Otolaryngology - Head and Neck Surgery.

A team led by Anna Giuliano, PhD, of the Moffitt Cancer Center and Research Institute in Tampa, FL, reported that, in addition to male sex and older age, high-risk oral HPV infection was also associated with sexual behaviors, including a higher number of male sex partners and female oral sex partners.

Oropharyngeal cancer caused by high-risk HPV infection is the most common HPV-associated cancer, Giuliano and colleagues noted. But little is known about oral HPV prevalence and genotype distribution in the general population

To address this knowledge gap, the team used data from a study called PROGRESS

(Prevalence of Oral HPV Infection, a Global Assessment) that included 3,196 participants from 43 U.S. dental offices and was conducted between November 2021 and March 2022. The participants provided an oral gargle specimen for HPV DNA and completed questionnaires regarding their sexual behavior.

The investigators reported the following:

Oral HPV prevalence was 6.6% for any detected genotype, 2% for high-risk (oncogenic) disease, 0.7% for HPV-16, and 1.5% for 9-valent HPV vaccine types.

Among HPV-positive participants, HPV-16 was the most prevalent genotype (12.4% among men and 8.6% among women).

HPV prevalence was higher in men than women and highest among men age 51 to 60 (16.8% for any HPV, 6.8% for high-risk HPV, and 2.1% for HPV-16) “In this cross-sectional study, oral HPV burden was highest among older men who may be at higher risk of developing oropharyngeal cancer,” the group concluded.

# CHAPTERS OF SPOHNC

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

*PLEASE NOTE: Some Chapters are not holding meetings in person at this time.*

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

Call to SPOHNC to find out more



*Featured above is SPOHNC's Gilbert, AZ Chapter Support group.*

Send us your SPOHNC support group photo (with permissions) to be featured here in a future issue!

SPOHNC

1-800-377-0928 or [info@spohnc.org](mailto:info@spohnc.org)

[spohnc.org](http://spohnc.org)

SUPPORT FOR PEOPLE WITH  
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