

SPOHNC

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



2023 ASCO ANNUAL MEETING

Thank you to the American Society of Clinical Oncology, for selecting SPOHNC to be part of their Patient Advocacy Pavilion. We were proud to represent SPOHNC alongside many patient advocacy organizations from around the country and globally. Such a great opportunity learning about new research and meeting with physicians and partners who will shape the future of this disease.

SPOHNC's Chapter News

Read all about it on page 6.

Massachusetts Patients & Survivors Needed!

Find out more on page 7.

Summer Champion of Hope

A shout out to a great man. Turn to page 8.

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How to Get Started With Meditation During Cancer Treatment

Kimberly Lowe, PhD

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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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How to Get Started With Meditation During Cancer Treatment

Kimberly Lowe, PhD

Meditation practice has been shown to calm the mind and body...

Meditation is becoming a more common part of cancer treatment, recovery, and survivorship, and for good reason. Meditation is a free resource to support people with cancer and has many meaningful benefits that can help them navigate the challenges of a cancer diagnosis and treatment. However, despite the incredible benefits of meditation, there's one big problem: People often think meditation is more mystical than it is, and they often don't stick with it because they have unrealistic expectations of what they need to do to be "good" at it.



You may think you need to sit in stillness and complete silence for long periods of time for meditation to make a difference in your life. But this isn't the case. And, if you're managing the responsibilities of a house, career, family, bills, and now a cancer diagnosis, that just isn't realistic. Here's what to know about getting started with meditation and how meditation can help you during cancer.

What is meditation?

Meditation is defined by the Cambridge dictionary as "the act of giving your attention to only one thing, either as a religious activity or as a way of becoming calm and relaxed." I've heard people describe it as "the place where I find my center," "where I go to get calm," "my happy place," and "falling back within myself."

Meditation is a practice of working with your mind to expand the peace you experience in life. Meditation is not daydreaming or trying to control your mind. Rather, it is a way of gaining

awareness of your thoughts and naturally allowing a state of peace to comfort you.

Eckhart Tolle, the spiritual teacher and author of *The Power of Now*, says, "One conscious breath in and out is a meditation." Meditation comes in many shapes and forms, and finding the way of meditation that works for you is the best way to set yourself up for success. What are the benefits of meditation?

Meditation can calm your body and mind and help you learn how to engage the "relaxation response," which is vitally important at all stages of your cancer experience. The relaxation response is a state of deep rest that activates the parasympathetic nervous system, which is responsible for the body's response when it is relaxed or resting. This allows your body and mind to relax and repair. Through regular meditation, you will become more familiar with feeling calm, and it will be easier to achieve that state during times of high stress, such as when you need treatments or are **undergoing scans**.

Meditation has also been shown in clinical studies to reduce **stress, pain, depression, anxiety**, and increase emotional balance, focus, creativity, and **memory**. These are critically important for everyone affected by cancer, including people with cancer, survivors, and caregivers.

How can I get started with meditation?

Wherever you are on your cancer journey—whether you are newly diagnosed, in treatment, in recovery, or a survivor—here are some tips for starting on your path of meditation.

1: Make yourself physically comfortable.

Most meditation teachers will tell you that the ideal meditation positions are sitting in a chair with your feet flat on the floor and your spine straight or sitting cross-legged on the floor with your spine straight. Unfortunately, these are generally not comfortable

positions for many people, including those with cancer, which can make it challenging to stick with your meditation practice.

Instead, I suggest letting yourself recline or even lay down. Allow your body to be fully supported. You may enjoy the meditation more, and you'll find a more profound sense of relaxation if your body feels good. If you find this causes you to fall asleep, try meditating at a different time of day. Or, better yet, let yourself enjoy a nice nap! Sleep is an essential part of your recovery, too.

2: *Start small.*

If meditation is new to you since your cancer diagnosis, start by setting your timer for just 1 minute. Sit, breathe, and relax for 1 minute. Do that for a few days, and then increase it to 3 minutes. Then, you can increase it to 5 minutes, 10 minutes, and so on. It's all about baby steps. If slowing down in this way makes you feel anxious, try putting the palm of your hand on your forehead and breathe in through your nose and out through your mouth slowly for at least 5 breaths.

Remember that a 5-minute meditation every day is better than a 30-minute meditation once a week. Celebrate your successes, 1 minute at a time!

3: *Create a dedicated place for meditation.*

Humans are creatures of habit, and we often connect positive or negative feelings with specific places, scents, and sounds. Doing something repeatedly in the same place, at the same time, or with similar sensory stimulants helps us fall more quickly into alignment with the purpose of that activity.

For these reasons, I strongly suggest setting up a dedicated place for your meditation practice.

It can be as simple as one side of your couch, a corner of your office, or even a whole room dedicated to your health and wellness. Whatever the location is, it needs to be a calm, quiet, and comfortable place you enjoy. Perhaps light a candle or play soft music to help cue your body that it's time to meditate and relax. Meditating at the same time each day or as part of a daily sequence—such as getting your pajamas on, brushing your teeth, and then meditating—can help your body know what to expect.

4: *Have realistic expectations.*



Be realistic when you first sit down to quiet your mind during your meditation practice. It's normal and even expected for your mind to be flooded with thoughts and worries when you finally have some quiet time. For most people, it's almost as if sitting down in the quiet invites random thoughts to invade their minds. This is called "monkey mind," and it happens to everyone.

You can set yourself up for success by knowing these invasive thoughts are coming. Allow your thoughts to come into your mind and then leave, like passing clouds in the sky. By not attaching to them or judging them, you will get more skilled at allowing your mind to feel more relaxed. This takes practice and can be incredibly challenging after a cancer diagnosis because this may be an unknown territory in your life. This is even more reason to be accepting and non-judgmental of yourself and to stick with your daily meditation practice. Some days will be better than others, and that's perfectly OK.

Regardless of how, where, or when you meditate, finding a pattern that works for you is the key to success. A few minutes every day will lead to positive results and will likely encourage you to meditate for longer next time. If it feels hard for you one day or you fall asleep, don't let that discourage you from trying again the next day or the day after. With a little bit of practice, your timer will be going off before you're ready to stop.

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Kimberly Lowe, PhD, has spent her entire 20-year career as a cancer researcher trying to improve diagnostics and quality of care for people with cancer. She is also the founder of Empower You, which offers mind-body tools specifically for those affected by cancer, including yoga, meditation, nutrition, guided self-massage, guided energy medicine, and art classes.

Head and Neck Cancer News

Neoadjuvant nivolumab, paclitaxel, and carboplatin followed by response-stratified chemoradiation in locoregionally advanced HPV negative head and neck squamous cell carcinoma (HNSCC): The DEPEND trial.

Oral Abstract Session – ASCO 2023 Annual Meeting – presented by Ari Rosenberg, MD

Ari Rosenberg, Aditya Juloori, Nishant Agrawal, John Cursio, Michael J. Jelinek, Nicole Cipriani, Mark W. Lingen, Rachelle Wolk, Jeffrey Chin, Melody Jones, Daniel Ginat, Olga Pasternak-Wise, Zhen Gooi, Elizabeth A. Blair, Alexander T. Pearson, Daniel J. Haraf, Everett E. Vokes; University of Chicago, Chicago, IL; Department of Radiation and Cellular Oncology, University of Chicago, Chicago, IL; University of Chicago Department of Surgery, Chicago, IL; Rush University Medical Center, Chicago, IL; University of Chicago Medical Center, Chicago, IL; University of Chicago Department of Radiology, Chicago, IL; Department of Medicine, University of Chicago, Chicago, IL

Background: The role of neoadjuvant immunotherapy in curative-intent head and neck squamous cell carcinoma (HNSCC) remains poorly defined. Survival for locoregionally advanced (LA) HPV negative (-) HNSCC remains poor with two-year survival of ~50%, and substantial treatment-related toxicity with standard chemoradiation (CRT). Given the activity of anti-PD1 in recurrent/metastatic HNSCC, we studied neoadjuvant nivolumab with chemotherapy and the feasibility of subsequent response stratified CRT in HPV(-) LA HNSCC.

Methods: The DEPEND trial (NCT03944915) is a phase II trial of nivolumab, paclitaxel, and carboplatin followed by response-stratified CRT for previously untreated stage IVA-B (AJCC-8th edition) HPV(-) HNSCC. The ultimate goal is to evaluate radiation volume and/or dose reduction to decrease long-term toxicities. Eligible patients received three 21-day cycles of nivolumab 360mg day 1, paclitaxel 100mg/

m2 on days 1/8/15, and carboplatin AUC5 day 1. Patients with $\geq 50\%$ reduction by RECIST 1.1 received response-adapted CRT to 66Gy with elimination of elective nodal volumes; $\geq 50\%$ reduction received standard-dose CRT to 70-75Gy. Post-CRT nivolumab 480mg every 4 weeks for 9 months was administered. The primary endpoint was deep response rate (DRR) defined as the proportion of patients with $\geq 50\%$ reduction. Tumor PD-L1 immunohistochemistry was reported as combined positive score (CPS).

Results: Thirty-six eligible patients started treatment between September 2019 and June 2022. Median age 59 (range 27-77), 22% female, 80% 20PYH smoking, 39% oral cavity, 19% oropharynx, 25% larynx/hypopharynx, 78% T3/4 and 78% N2/3. PD-L1 CPS ≥ 1 in 58%. The DRR with nivolumab/chemotherapy was 54% (95% CI 0.37-0.72), which met our statistical endpoint. The ORR was 89%. CRT stratification was as follows: Response-adapted CRT (n = 19) and standard-dose CRT (n = 16). At a median follow-up of 14 months, 2-year PFS and OS were 64% (95%CI 0.41-0.80) and 76% (95%CI 0.53-0.89), respectively. By CRT stratification, 2-year PFS was 79% and 46% in response-adapted and standard-dose CRT, and 2-year OS was 86% and 67% in response-adapted and standard-dose CRT, respectively. One patient died from disease progression during neoadjuvant therapy. 2-year distant control in response-adapted and standard-dose CRT arms was 100% and 63%, and 2-year locoregional control was 85% and 92%, respectively. PD-L1 CPS ≥ 1 and ≥ 1 demonstrated DRR of 75% and 27%, respectively (p= 0.01).

Conclusions: Nivolumab-based neoadjuvant chemoimmunotherapy led to deep responses, and response-adapted CRT was associated with favorable survival and locoregional control. PD-L1 expression was predictive of deep response to nivolumab based neoadjuvant therapy. Late toxicity analysis between treatment arms is planned. Clinical trial information: NCT03944915. Research Sponsor: BMS.

Find us and connect with us at spohnc.org

Chapter News

SPOHNC's Medford, Oregon and Dallas, Texas Chapters Welcome Guests

SPOHNC is grateful to our SPOHNC Chapter Facilitators and Co-Facilitators and all of our volunteers who go the extra mile to connect with patients, survivors and their families to ensure that each one knows they are not alone in their cancer journey. Several of our SPOHNC Chapters have been holding special events during their meetings, or inviting guest speakers to come and present on topics that are important to patients and survivors.

SPOHNC's Medford, Oregon Chapter Facilitator, Jennifer Lewellyn, continues conducting monthly meetings the 1st Friday of each month.

Kudos to Jennifer for doing an amazing job with her group and for recruiting guest speakers to join her monthly meetings!

Recently, the group heard from guest speaker, Sherri Sexton Parson, RD, who spoke about nutrition during recovery.

SPOHNC's Dallas, Texas Chapter "Support Team" Facilitator, Jack Mitchell, also has some great speakers at their meetings. Just recently, the group enjoyed a presentation by Dr. Randy Hughes on 'The Role of Immunotherapy' in cancer treatment. Jack was also able to make the meeting a hybrid, so that those who could not attend in person, could still attend the meeting via Zoom.

The group had another recent guest speaker...Dr. Vladimir Avkshtol (Dr. 'A') gave a presentation on Adaptive Radiation Therapy (ART) which is going through a trial at UTSW, where the meeting is held each month. They have 4 radiation machines that not only radiate patients



but have the capability of completing a CT or MRI Scan while the patient is locked down on the table with their mask, so the next day's radiation treatment can be adjusted for weight loss/gain, swelling, or reductions of the tumor and any body changes, making the radiation more accurate, and in some cases, reducing the number of radiation treatments required to rid the disease from the patients. One new attendee

is being treated by Dr. 'A' and his radiation sessions were completed in 15 sessions instead of 30+.

The group also recently held a caregiver celebration, where the Support Team Meeting focused on the awesome Caregivers who helped each patient along their cancer journey. Each Survivor introduced their Caregivers and gave the group praises for their assistance in their journey.

What is your Chapter doing? Do you have guest speakers, or special topics or celebrations? Let us know so we can share your events and some photos in an upcoming issue of *News from SPOHNC*. Share your news so we can highlight your group!!

SPOHNC extends
our sincerest apologies to

Charles Banta
2022 Patron Donor

on the omission of his name
from the Spring 2023 issue.
Thank you for your continued support
of SPOHNC

Calling All Massachusetts Head and Neck Cancer Survivors!



Massachusetts Oncology Patients, Survivors and Supporters (MOPSS) Update

Are you looking for your insurance company to pay your dental expenses???

Massachusetts Oncology Patients, Survivors and Supporters (MOPSS) is working with elected representatives in Massachusetts on Bill #1094 which if passed, would require insurers doing business in Massachusetts to cover medically related dental treatment.

This effort is currently being endorsed and fully supported by SPOHNC, and its Massachusetts Chapter Support Groups, as well as Dana-Farber Cancer Institute, Massachusetts General

Hospital, the Massachusetts Society of Otolaryngology/Head and Neck Surgery, Inc., the Massachusetts Society of Clinical Oncologists, Mass General Brigham – Mass Eye and 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. We expect this list of supporters to grow as our outreach continues.

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

If you live in Massachusetts, please contact your state representative or state senator to ask for their support for this bill!

If you live in Massachusetts and would like to join the MOPSS Committee, we are actively seeking more committee members, so that our voices will be heard! Please contact Tom Healy at mopssma@gmail.com or by phone at 781-686-3774 for details about upcoming meetings, and how you can help!!

Like, follow and share their new Facebook page at <https://www.facebook.com/profile.php?id=100093156990569> or by searching Massachusetts Oncology Patients, Survivors and Supporters on Facebook.

If this bill passes in Massachusetts, it can be the model program for other states to follow. Let's all make it happen!!

Survivor News Survivor, Hank Deneski

The Dayton VA held their Annual Cancer Survivor's Day event on June 2, 2023 from 10:00 – 3:00. The event hosted lunch, walks around the campus every hour in honor of those that have been diagnosed with cancer, and informational booths in the multipurpose building for participants to browse through.

SPOHNC's Dayton, Ohio Chapter Facilitator, Survivor Hank Deneski, participated once again in this important day by hosting a table, along with 3 other head and neck cancer survivors. Thank you, Hank, and friends, for continuing to raise awareness of oral, head and neck cancer, and SPOHNC.



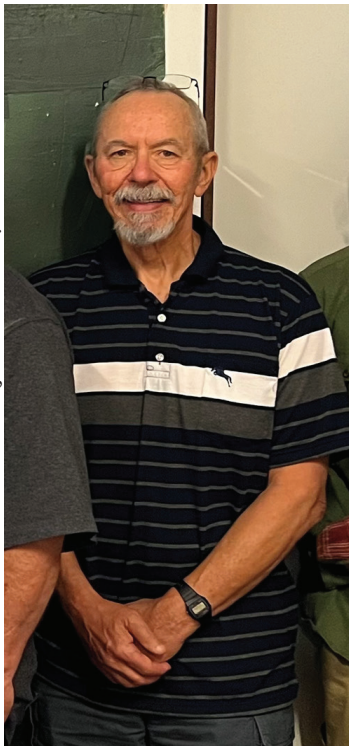
Summer Champion of Hope

Les Norde - SPOHNC's Gilbert, AZ Co-Facilitator & Scottsdale, AZ Chapter Facilitator

Survivor and SPOHNC Gilbert, AZ Co-Facilitator and Scottsdale, Arizona Chapter Facilitator, Les Norde, is an inspiration to us all.

He joined our SPOHNC family in 2005 and has maintained his annual membership and support of SPOHNC every year, ever since. Thank you, Les, for your continued commitment to oral, head and neck cancer patients and survivors, and SPOHNC.

It takes a very special survivor to make the commitment to assist in facilitating a SPOHNC Chapter support group, much less 2 of them! There are monthly meetings, follow ups, and speakers and activities to plan for, in addition to maintaining the connection with group attendees who lean on each other throughout the year for support. Every group attendee becomes a family member, and the bonds and connections grow stronger over time.



Les always goes above and beyond, and in fact, in support of April Awareness Month in 2021, he even took a nighttime drive to Gilbert, Arizona, to see the Water Tower illuminated in our SPOHNC colors, to raise awareness of oral, head and neck cancer. The photos we share with you each year are compliments of Les and his great photography skills...Thank you!!

During the pandemic, Les and his groups in Scottsdale and Gilbert remained both flexible, and committed, as they continued to meet via Zoom each month. While the attendance was less than the previous in person meetings, there were still new people joining for the caring and support that the groups so effectively deliver. SPOHNC is forever grateful for this unwavering commitment to helping others along their cancer journey.

Les and his attendees are always willing to welcome some special guests to their meetings. Les shared with SPOHNC that quite regularly, they have requests to present and/or visit their meetings from students at various schools in the Phoenix area especially Midwestern University and AT Still Dental School in Mesa. Les and the group always welcome these visits because the guests educate attendees by answering questions they ask about current treatments being taught to the students. Students truly appreciate the opportunity to talk to cancer patients/survivors in various stages of recovery. It's a win-win!

SPOHNC Chapter Facilitator Keri Winchester, MS CCC-SLP is the Co-President of the Les Norde Fan Club. She shared with us...“a shout out to Les for his tireless dedication and wonderful attitude that means so much to so many.”

SPOHNC's Executive Director, Mary Ann Caputo, said it best...

“Thank you, Les, for all your support to the group. Your invaluable time, dedication and positivity is so important to patients and their loved ones. We know that they appreciate your commitment and kindness as we do!”

For these reasons, and so many more, it is our pleasure to honor you as SPOHNC's Summer 2023 Champion of Hope!!

“We have a great group with a number of very giving and helpful folks. Some of them are facing and have faced some extremely tough issues and yet, they are always positive.”

~ Neil

Two Delicious Dishes!



Tortellini Soup
— RECIPE —

INGREDIENTS:

- 1 can chicken or beef broth (any brand)
- ½ pkg. frozen meat tortellini
- 1 c. frozen peas/carrots (optional)
- Grated Parmesan cheese (optional)

Nutritional Information Per Serving:

Calories 386(kcal), Total Fat 7(g), Saturated Fat 3(g), Cholesterol 48 (mg), Sodium 1020(mg), Carbohydrate 53(g), Dietary Fiber 2(g), Protein 26(g).

Add one can of water to beef or chicken broth. Bring to a boil. Add tortellini & vegetables if desired. Cook 10 to 15 minutes. Serve with grated Parmesan cheese. Serves 3.

Jane Z. - NY

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Strawberry Pudding
— RECIPE —

Ingredients

2 env. Knox unflavored gelatin	1 tsp. almond extract
1 qt. fresh strawberries	1 qt. fresh strawberries
½ c. cold water	¼ c. sugar
1 c. skim milk	(or 1 tsp. sugar substitute)

In a 5 cup blender, add ½ cup cold water. Sprinkle unflavored gelatin over the water & let stand for 3-4 min. In a small saucepan, heat skim milk until boiling. Add hot milk to blender & process on high speed until strawberries are pureed. Pour into dessert dishes or bowl & chill until set. Yields 8 (4 ounce) servings.

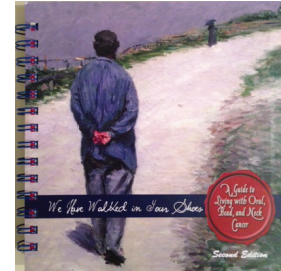
Nutritional Information Per Servings:
Calories 139(kcal), Total Fat trace(g), Saturated Fat trace(g), Cholesterol 1(mg), Sodium 71(mg), Carbohydrate 32(g), Dietary Fiber 2(g), Protein 3(g).

Hildegard V. - NY

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



DIGITAL EDITION available now on our website for \$7.99

PRINT EDITION \$14.95 includes shipping and handling

For Bulk order discount pricing contact SPOHNC at 1-800-377-0928 or email us at info@spohnc.org

“SPOHNC has been an incredible resource for me and I’ve found it has been key in the healing process for head and neck cancer patients since 1991.”

– Paul W.

Praise Anthem - A Celebration Story

by Survivor, Melissa Vincent

My spirit stirred joyfully in response to the music pumping through the speakers of my BMW. As the car kept pace with traffic, my thumb kept a synchronized beat to the tune by tapping the smooth leather gear shift. Simultaneously, the sun was performing a spectacular spring morning show. Its orange haze was bright enough to warrant sunglasses so I reached for a pair inside my checkered backpack sitting on the passenger's seat beside me. As they slid onto my nose I celebrated God's glorious attention to detail and began singing out loud.

'I'm changed by your mercy.
Covered by your peace. I'm living
out the victory. Doesn't mean I
won't feel the heat.' As the words
poured off my lips, I imagined
tiny music notes floating-up from
behind the steering-column, happily
dancing their way up the windshield
before disappearing through the
open sunroof. Then, rather subconsciously, the
thumb tapping the gearshift raised with its hand
in worship as I belted out, 'I can face anything!
Cause You're here with me! I can do all things!
Cause You strengthen me!'

The track, titled Fires, is by Christian artist
Jordan St. Cyr. I don't just hear it and sing it,
but I also feel it. Suffice it to say, by the time
the chorus hit, I was practically yelling. 'You've
walked me through fires. Pulled me from flames.
If you're in this with me. I won't be afraid.
When the smoke billows higher, oh and higher.
And it feels like I can barely breathe. I'll walk
through these fires, cause You're walking with
me.' Eventually my voice subdued to silence
as warm tears escape from behind the sunglass
lenses. The remaining miles would be spent
quietly reflecting upon the circumstances that
had made Fires my anthem to begin with.

A few years before the song was released, I'd
been managing a nagging irritation on my



tongue. I had been tolerating it for nearly six-months when a coupon came in the mail from a local dentist offering a full exam for only \$49. I called immediately. By God's grace, I was offered an appointment for the very next day and I took it. My hygienist was Courtney, and I liked her immediately. After she cleaned my teeth she did a simple oral cancer exam. It consisted of lifting up my tongue and looking at the underneath-side of it. Up until the screening, Courtney and I had been chatting lightheartedly about being boy moms and fashion and designer handbags. Fun things. But her voice shifted to a less jovial tone after she examined my tongue. She leaned into my shoulder and softly said, "You have a few faint gray lines under your tongue. I'll tell the dentist about them, but you should see a specialist." She added, "We know a good oral surgeon close by. I'll get you his business card before you leave."

I remember studying the name and credentials of the oral surgeon on the card as it balanced between my thumb and ring finger. I flipped it over and back a few times before finally declaring silently to myself, "This isn't happening! I'm always the caretaker, not the sick person. I'm fine. I don't have oral cancer. Those gray lines are nothing. Besides, Courtney said they are faint. I'm sure they'll go away." I tossed the card into the gift bag I'd received, along with a free toothbrush and floss, and left the appointment. I would be back in the dentist's care a week later though.

In addition to the gray lines on my tongue, two cavities had also been discovered. I waited to have them filled because I wanted to take advantage of the sedation option the dentist offered. By choosing to be sedated, I was required to have someone else drive me home so my husband Roger agreed to be my chauffeur. Roger managed to get me home while I was still pretty much asleep. When I was finally completely awake I felt fantastic except that I sensed an unusual tension from him. I noticed his iPhone clenched in his right hand and then we made eye contact. "Melissa," he said sternly, "You have to go see that oral surgeon. After your procedure was over today, the dentist told me that the lines under your tongue have gotten worse." Then it hit me! Roger had been using his cell phone to Google information about what the dentist shared with him. I knew whatever he'd been reading must have been horrible for him to speak to me so seriously.

Ultimately I acquiesced and called the number on the business card I'd tossed out of view the week before.

Over the next six-months, I'd be in the care of the oral surgeon Courtney referred me to. She was right. He was great at his job, and I also liked him very much. He performed a biopsy of my tongue the first month and an ablation the second month. Both were extremely painful. The biopsy required an inch-long incision and stitches on my tongue, and the ablation felt as though my taste buds had been burnt off with a Bic lighter. Each procedure had been done in an effort to keep my newly diagnosed, precancerous condition, under control. I had Moderate Dysplasia and there was no treatment except to wait and pray that it would dissipate.

Unfortunately while we were waiting, the Covid-19 pandemic hit the United States. The virus forced my doctor to close his office and two-months would pass before he would be able to examine my tongue again. By month five of the endeavor, I was finally back in his care and my mouth was a mess. I had yellow and red blisters the size of puffed rice cereal covering my tongue. The pain was so intense I could hardly stand to talk or eat. I watched my oral surgeon's eyes as he looked in my mouth. We'd been partners in my care since December 2019.

I trusted we'd done the best under the lousy circumstances of managing my precancerous condition while we all dodged Covid. As I sat motionless in the exam chair, I watched his eyes through his glasses and the reflection of my mouth on his lenses which had been created from the overhead light. While he intently examined my mouth there was complete silence between us. Finally he confirmed what I already knew in my soul. The Moderate Dysplasia had progressed. I left that day with a referral for an oncologist and barely made it out of the fourth-story office and back to my car before completely sobbing.

The oncologist ordered another biopsy and a PET-scan. They confirmed that I had Stage I Squamous Cell Carcinoma and a nickel-sized tumor housed in the left side of my tongue.

Roger and I tried convincing ourselves that Stage I made my cancer less of a big deal. But it wasn't actually any less. Squamous cell cancers are very aggressive and rapid moving cancers that have the potential to travel quickly to bones and other soft tissues.

Fortunately the tumor could be removed, but it meant I'd also lose half my tongue. The procedure, called a glossectomy, would allow my surgeon to reconstruct my tongue with donor tissue from my own wrist and an artery from my arm. I would also have lymph nodes removed from my neck to ensure the cancer hadn't spread anywhere else in my head or body. Then, one of the last steps in the six-hour surgery would be a skin graft. The skin would come from my left leg, just below my hip, and it would be used like a band-aid to help cover my wrist. It sounded insane. But if this surgery would empower me to keep being Roger's wife and Ryan's mom, I would absolutely do it.

Ironically, my BMW's license plate reads PRAY BIG. Praying is a practice I've honored my entire life. So during the three-week wait between scheduling my surgery and having it done, I prayed intently for God to heal me. I prayed He would supernaturally remove my tumor and that my preoperative PET-scan would prove the cancer was gone. I spent countless hours, every day on my back porch, searching for content in the Bible about people who had been healed. When I found evidence of it, I'd pray those scriptures over myself while inserting my own name into the text as I recited it.

The doctor who would perform my glossectomy is very highly revered across the United States for his mastery of oral cancer surgery. He and I had only logged a couple of hours together during my preoperative appointments, but I trusted him implicitly. During those appointments, I had come to discover that we share a deep and abiding trust in Jesus, which allowed me to fully surrender to his care. -And I would have to. My petitions to the Lord had not rendered the supernatural healing I'd pleaded for. Instead, I'd need to concede to the surgery in order to save my life.

The glossectomy went perfectly. The entirety of the tumor was removed and I began speaking with my new tongue in a matter of days. My lymph nodes showed that the cancer had not spread and I would not need any follow-up radiation or chemotherapy. It took two months for my wrist, arm, and skin graft site to heal, but the scars are remarkable. They have become my storybook and I point to them regularly when I share my praises about defeating oral cancer.

I have finally reached my destination. Before getting out of the car, I press repeat on the stereo one last time. As Fires

plays again, I close my eyes so my heart can hold fast to the lyrics as they halo my soul. ‘I remember how You showed me the price of my redemption. Lord, how could I question when You proved that You’d die for me. You’ve walked me through fires, pulled me from flames...’ The song ends and I add an audible, “Amen!” before turning off the car’s engine. The BMW is silent, but I won’t ever be. Surviving oral cancer has given me too much to sing about.

~ Melissa Vincent
melissa@simplyspoken.life

Melissa is a member of SPOHNC’s National Survivor Volunteer Network. She’s also a writer and public speaker. To read more stories about her oral cancer victory, please visit SimplySpokenLife.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 to find out how you can help someone who is just beginning their journey.

Call us at 1-800-377-0928, or email us at info@spohnc.org.

Head and Neck Cancer Research Project

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

IQVIA™ (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.

An advertisement for an IQVIA research project. It features two women walking outdoors, both wearing pink face masks. The woman on the left is older with white hair, wearing a light blue top and a white cardigan. The woman on the right is younger with dark curly hair, wearing a white long-sleeved shirt and dark pants. The text 'Share your experience living with Head and Neck Cancer' is overlaid on the image. The IQVIA logo is in the top right corner. At the bottom, there is a blue box with white text: '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'. To the right of this box is a QR code and the text 'SCAN HERE TO SEE IF YOU QUALIFY'.

In Memoriam - Dave Noble

It is with our deepest sympathy that we share with you the passing of a beloved member of our SPOHNC family. David “Dave” Dudley Noble of Rockwall, Texas passed away at home on April 15, 2023, at the age of 67 years old.

Dave was born on November 25, 1955, in Iowa City, Iowa to Dr. Dudley and Norinne (Fenner) Noble. Dave grew up swimming, fishing, and hunting and fondly looked back on the times he had with his parents, younger brother Jeff, and youngest sister Julie. He also grew up relic digging, which spurred a lifelong interest in history and admiration for veterans and the armed forces.

Dave graduated from West High School in 1974 and went on to become a swimmer for the Hawkeyes, and the third generation in his family to be an athlete at the University of Iowa.

After graduating college, he started his career off in the trading of rare coins and paper money, becoming an expert and even contributing to 5 books on the subject matter. In 1980, he moved to Dallas to work at Steve Ivy Rare Coins, where he met his wife Leslie.

Craving stability for his dream of building a family, he decided to change his path and pursued a career in real estate. Throughout his 28-year-long career, he developed many large office and industrial buildings and earned a Lifetime Achievement Award as well. But despite that, his self-proclaimed greatest accomplishments within the industry were in all the friends he made, in becoming a mentor to many who ended up achieving great things, and in being a champion of leading with the heart, touting the importance of integrity and compassion. Meanwhile, he built the family he had always wanted, welcoming three sons Chad, John, and Nick into the world. Dave was especially proud of his sons and would share stories about them all the time.

In 2005, Dave was diagnosed with tongue cancer, and soon after that he became a member of our SPOHNC Family. Upon becoming a member of SPOHNC he learned of a chapter in Dallas where he attended many meetings. He

became good friends with the Facilitator, Dan Stack and would always speak very highly of Dan until his unfortunate passing in 2017. Dave was very upset about Dan’s sudden death and would always share stories about their close friendship, and how much Dan supported Dave through his cancer journey.

He truly enjoyed connecting with people, and he would do so when he was in the waiting rooms at appointments. He built his own following, and others looked at him as their inspiration. He shared with us that he began handing out small crosses with Psalm 23 written on them to those he met along the way, sharing his newfound faith.

In 2020, Dave finally became an “official volunteer” for SPOHNC’s National Survivor Volunteer Network, and he supported a half dozen newly diagnosed patients who came to SPOHNC seeking inspiration. There was no one more inspiring than Dave!

Dave was a natural born storyteller, with a wonderful sense of humor. He would call us at the SPOHNC national office, and share stories with us very often. He loved to call and chat, and no matter what we were up to, we always had time for a good Dave story.

He would keep us in stitches sometimes with his humor and his wonderful, kind heart. SPOHNC’s Executive Director, Mary Ann Caputo said “I will never forget one Friday he called, and he spoke about his swimming days. At that time, he didn’t know how to send a picture attached to an email, so he texted me a photo of him in his high school swimming trunks boasting about the great physique he had back then, and he did. He always had a way of filling our hearts with laughter.

Dave shared with us that he found a new love – of painting. It seemed he had a gift he never knew about. One day in our conversation he mentioned he had taken a painting class. We asked him to send some photos, and wow... he was quite handy with that paintbrush! Unfortunately, the class he took at Michaels was put on hold due to the pandemic and it never returned. That saddened our dear friend because he wanted to do more. That was Dave – he always wanted to do more.

To Dave’s family, and friends, our hearts are broken for you all. We loved Dave and loved hearing from him. He leaves his wife and family a wonderful legacy that we hope will help heal their pain and sorrow. He touched many lives, and we want to honor him especially for all the support he gave to others even though he was going through his own challenges. We will keep you all in our thoughts and prayers. God bless you all.



Head and Neck Cancer News

Randomized phase I/II trial of TheraT vectors expressing HPV16 specific antigens with neoadjuvant chemotherapy followed by transoral robotic surgery (TORS) or risk/response stratified chemoradiotherapy (CRT) for locoregional HPV16+ oropharyngeal cancer (OPC).

TPS6115 Poster Session - ASCO 2023 Annual Meeting

Ari Rosenberg, Nishant Agrawal, Aditya Juloori, Theodore Karrison, Jeffrey Chin, Rifat Hasina, Zhen Gooi, Elizabeth A. Blair, Daniel J. Haraf, Evgeny Izumchenko, Alexander T. Pearson, Everett E. Vokes; Department of Medicine, University of Chicago, Chicago, IL; The University of Chicago, Chicago, IL; University of Chicago Medical Center, Chicago, IL; University of Chicago, Chicago, IL

Background: HPV+ OPC is associated with excellent survival, yet standard therapy leads to substantial treatment-related toxicity. Among various de-escalation strategies, response adaptive de-escalation which selects pts based on neoadjuvant response is promising with excellent survival and reduced toxicity. Strategies to further deepen responses may allow more pts to be de-intensified which may improve survival and further reduce toxicity. As generation and maintenance of the HPV16+ malignant state of a cell requires the consistent expression of HPV-specific E7 and E6 oncoproteins, they represent a potential immunotherapy target, inspiring the development of HPV-specific immune activators, such as HB-200 platform. This platform contains two replicating live-attenuated vectors based on either lymphocytic choriomeningitis virus (HB-201) or Pichinde virus (HB-202), which express the same non-oncogenic (but highly antigenic) HPV16 E7E6 fusion protein and infect antigen presenting cells to induce and activate tumor-specific T cell responses. Data from in vivo models and early phase clinical studies indicate that HB-201 monotherapy and HB-201/HB-202

alternating two vector therapy induces a robust antigen-specific circulating T cell response and anti-tumor activity, suggesting potential to provide therapeutic benefit to pts with HPV16+ OPC. Based on these studies we hypothesized that incorporation of the HB-200 platform with neoadjuvant chemotherapy followed by risk/response-stratified de-escalation in our ongoing randomized phase I/II study may deepen responses and facilitate de-escalation in a greater proportion of pts (NCT05108870).

Methods: Eligible pts must have previously untreated HPV16+ OPC with T3-4 or N2-3 (AJCC-7th edition). Very low-risk disease with T1-2 and N0-1 are excluded. Pts receive neoadjuvant therapy with either HB-201 or HB201/HB-202 alternating two-vector therapy for 3 doses in combination with carboplatin AUC 5 day 1 and paclitaxel 100mg/m² on days 1/8/15 of 21-day cycle for three cycles followed by risk/response adapted locoregional therapy with transoral robotic surgery (TORS) or RT to 50Gy (single-modality), CRT to 50Gy with cisplatin (intermediate de-escalation), or CRT to 70Gy with cisplatin (regular dose CRT). Eight pts have been enrolled in phase I portion with planned 74 pts (37 pts per arm) in phase II. The primary endpoint is deep response rate defined as proportion of patients with ≥ 50 shrinkage per RECIST v1.1. Secondary endpoints include OS, PFS, locoregional and distant control, and safety/ tolerability. Exploratory analyses will include cell free HPV-DNA, and tissue/blood-based assessment of specific anti-tumor immunity.

Clinical trial information: NCT05108870. Research Sponsor: Hookipa Pharma

“Thank you so much for connecting me to someone who has suffered through the same issues. It is always helpful.”

~ Christine

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!

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