

SPOHNC

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



Celebrate the Caregiver in Your Life!

November is National Family Caregiver Month. We salute you all, both past and present, and we pay tribute to you, for your selfless dedication, for taking on the hard things, and for always being there for your loved one, no matter what the day brought to you.

November Champion of Hope

SPOHNC is grateful.
Turn to page 6.

Welcome Karen Ulmer, MS, RN, CORLN

Read more on page 11.

In Memoriam - A Devoted SPOHNC Family Member

SPOHNC pays tribute on page 12.

Fear of Recurrence

Nathan Sattazahn, M.Ed, NCC, LPC

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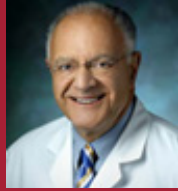
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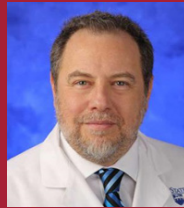
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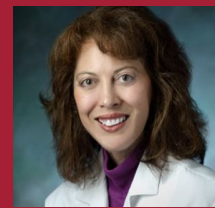
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Chris Leonardis

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Understanding and Managing Cancer Recurrence Fears

Even before I obtained a degree in counseling and elected to work with cancer patients, my life was impacted by cancer. Although I have not been diagnosed with cancer, I have witnessed the effects it has had on my friends and family. I recognized early on that cancer not only impacts an individual's physical health but also their psychological health. It often contributes to a potentially problematic shift in an individual's perspective when considering their identity, what they can control, and their overall health future.

For the past several years, my role as a Licensed Professional Counselor with the Penn State Cancer Institute has offered me the opportunity to provide individual, family, and group counseling services to patients being treated for oral, head, and neck cancers. Providing care to these individuals and their family members has offered me the opportunity to better understand common issue that these patient face during their cancer journey as well as common fears that develop – the most prominent being the fear of cancer recurrence.

Facing a cancer diagnosis is a profound life experience. Even after successful treatment, the fear of recurrence can linger, casting a perspective of doubt on your continued path to recovery. This fear is entirely normal, but it's crucial to learn how to manage it effectively to regain control over life and move forward with confidence.

A useful starting place to better understand how to manage this fear is to consider how it develops and the impact a fear of recurrence can have on an individual's perspective. We'll do so with use of an example outside of cancer.

Allow yourself a moment to reflect on a recent drive, potentially a commute to work or a trip to complete an errand. Can you recall this commute in its entirety from start to finish in great detail? It's likely that you cannot – unless, of course, something out of the ordinary occurred.

Alternatively, let's imagine while on your commute you were involved in an accident. It's likely that tomorrow, next month, and perhaps even next year, you could recall most – if not every – aspect of that specific commute. It is also likely that you would begin to experience a shift in your perspective when making or considering future drives. Perhaps you would avoid that route or leave at a different time or develop anxiety about driving in general. That shift in perspective is likely being influenced by this lone incident, an outlier in the context of your driving history and not the norm.



I find that a similar shift in perspective can occur with individuals who receive a cancer diagnosis, complete their care, and attempt to move forward with their lives. These individuals begin to view their life through a lens that promotes awareness of the potential for negative outcomes and negative impacts rather than through a lens that allows for awareness of what remains normal in their lives or what may be within their control. The root of this perspective shift likely lies in a cancer patient's need to feel safe and their belief that by considering their future and potential outcomes, they can plan and prepare for future health outcomes, promoting a feeling of safety. For many, this heightened awareness of the impact that cancer has had on their lives and the consideration of the impact if would have if it were to return, perpetuates itself. As they continue to grow in their awareness of potential impacts, the more they allow them to be the focus when considering their health and wellness.

To help address fears of cancer recurring, I often encourage the individuals I work with to consider alternative perspectives and promote efforts to live life in the moment by being mindful of and acting on what is within their control.

Of course, it is important to first recognize and acknowledge that the fear of cancer recurrence is a valid and natural response to a life-altering experience. By acknowledging this truth and giving yourself permission to be present and evaluate these thoughts, you open the door to understanding, acceptance, and healing.

To help in managing this change in perspective and to become more mindful of its impact, I offer the following recommendations.

Be open and honest with your medical team. Maintaining open lines of communication and seeking education from your medical team will allow for a trusting relationship to develop,

help create a sense of partnership, and allow you to become comfortable asking questions, expressing concerns, and seeking clarification.

Understanding the nature of your cancer, treatment options, and potential outcomes, is valuable information that can be used to aid in managing your thoughts about the future of your health and the unknown. This information will allow you to make informed choices about your treatment and may allow for a sense of control in a time where it can be easy to feel helpless. I urge you to be aware of the temptation to avoid these conversations due to fear of the information that you will receive. Avoidance will only offer temporary relief and will likely increase future anxiety issues and feelings of vulnerability. Expressing concerns, having your feeling heard, and receiving reassurance are valuable tools for when you are feeling vulnerable.

Work to develop a positive yet realistic outlook on treatment. Setting realistic and achievable goals will allow you the opportunity to celebrate small victories and milestones. This helps boost your confidence, provides a sense of accomplishment, and fosters an open mindset and determination. Striking a balance between being positive and realistic will allow you to make informed decisions about your health care while not being unduly influenced by the fears associated with negative outcomes. This may also help to strengthen your resilience and allow for you to maintain a healthier perspective about potential setbacks that you may experience while receiving or recovering from care and moving forward with your life.

Practice gratitude. Actively practicing gratitude can be a powerful tool for altering an individual's perspective while facing the challenges of cancer and fears of cancer recurrence. An individual's life is rarely all negative, even though it may feel that way during challenging moments. During even the most challenging moments, an individual can find relief by acknowledging the potential kindness they are receiving, the connections they are making with their loved ones, or the benefits of their remaining health and abilities.

Practicing gratitude can take many forms such as the use of daily affirmation lists, keeping a positivity journal, or conducting periodic body scans that focus on recognizing the parts of the body that feel well or are relaxed. Whatever method is used, choosing to actively practicing gratitude helps to re-frame negative and unwanted thoughts.

Seek connections with others. No one should face the cancer treatment process or fears of cancer recurrence alone. Connecting with friends, family members, or support groups can offer a crucial source of understanding and empathy. The desire to connect emotionally with others is instinctive and caring for others also provides us validation when we feel cared about in return. During times of need or when facing the unknown, communicating your needs and fears can help create a realistic outlook on the future, aid you in being grateful, allow for you to be present, and promote a sense of control in your life.

Follow a daily routine. Engage in daily activities that allow you to find joy and be present in the moment – whether completing daily chores, exercising, or connecting with your support system in conversation. During the course of your day, allow yourself to bring your full attention to the task at hand. Notice the colors, textures, sounds, and sensations involved, and give yourself credit for the efforts that you are making. Engaging fully in these activities and offering yourself recognition for your efforts will allow for a more meaningful experience. It will also help you to achieve a sense control in the moment you're living in, deterring you from having thoughts of the future and unknowns with your health.

Practice mindful breathing when feeling overwhelmed. Find a quiet and comfortable space where you won't be disturbed. Sit or lie down in a relaxed position, place your hands on your lap or by your sides, close your eyes, and begin to focus your attention on your breath. Take slow, deep breaths, paying close attention to the sensation of the air entering and leaving your mouth and nose or the rise and fall of your chest and abdomen. Allow your breath to flow naturally, without trying to control it. If your mind starts to wander, gently bring your focus back to your breath, engaging all your senses in this process by noticing the temperature of the air, the rhythm of your breath, and any subtle movements in your body. Practicing this regularly and gradually increasing the duration of your practice as you become more comfortable will help you to calm your mind during difficult moments, reduce your overall feelings of stress, and promote a greater sense of presence in the moment.

Seek professional help. Consider talking to a therapist or counselor who specializes in cancer-related issues. These individuals can provide you with additional coping strategies, much needed support, and a safe space to discuss your cancer recurrence fears.

Managing the fear of cancer recurrence is a journey that requires patience, self-compassion, and a multifaceted approach. By acknowledging your emotions, seeking support and information, and adopting practical strategies for managing your perspective, you can take significant steps toward regaining control over your life and addressing your fear of cancer recurrence. Remember, you are not alone, and there is strength in reaching out for help. Just as it takes a team of professionals to diagnose and treat cancer, it helps to have a team of professionals

and supporters to help overcome fears of recurrence. With time and practice, you can improve your resilience and move forward with confidence to embrace the possibilities that lie ahead.

I hope these observations and suggests help you approach your own cancer recurrence fears or allow you to help others in your life facing those fears. For more information, please reach out to your cancer team or to your nearest SPOHNC.

Editor's Note: Nathan Sattazahn, LPC earned his undergraduate degree in psychology from Misericordia University, a graduate degree in counseling from Kutztown University and an LPC license from the state of Pennsylvania. He has worked as a counselor for the past 11 years in agency, private practice, and hospital settings, and has been part of Penn State Health for the past 5 years and works primarily with cancer patients and family members of cancer patients receiving treatment at the Penn State Cancer Institute.

Holiday Eating Tips

From the desk of Jack Mitchell - Survivor and SPOHNC Dallas, TX Chapter Facilitator

If you're invited to a party:

- Check with the host to see what they are serving and ask if you could bring something if there isn't anything on the menu that you can eat.
- If you need thickened liquids, bring your own thickener and container so that you can premix your fluids prior to the party.
- Let the person giving the party know of your special needs and offer some suggestions of foods that everyone could eat or ways they could help you. For Example: If you have decreased saliva production, let them know that you need extra sauces or gravies to moisten foods.

If you are having problems maintaining or keeping weight on:

- Choose dark turkey meat as it has more fat, calories and tends to be moister.
- Add margarine to vegetables. This also helps increase the moisture if you're having problems with decreased saliva production.
- Add whipped topping made with real cream to your pumpkin or other cream type pie.

- Consider having cream soups as an appetizer as they tend to be higher in calories.
- Add cream sauces or cheese sauce to your vegetables.

If you're having problems with taste alterations:

- White Turkey meat is blander if you have problems with stronger tasting meats.
- If you have a metallic taste when eating meats and other foods, you may need to skip the gravy.
- Experiment with different spices in seasoning your vegetables if the foods don't have any taste. You may need to add additional seasoning to your vegetables after.



November Champion of Hope

Tracy Lautenbach Hynes, Philadelphia, PA SPOHNC Chapter Facilitator

This month, when we celebrate what we are thankful for, we are full of gratitude for our November Champion of Hope. Tracy Lautenbach Hynes, MSW, LCSW, OSW-C has been the Facilitator of the SPOHNC Penn Philadelphia Support Group at Abramson Cancer Center since it formed in 2009. For almost 15 years, the group has been like a large family, standing by each other through diagnosis and treatment and beyond. Tracy has always made sure that every newly diagnosed patient feels fully supported, and able to find the information they need, at any time.

As one of SPOHNC's messengers, Tracy always has a supply of SPOHNC brochures at the ready, so that patients and survivors can become aware of our programs and services of support. She has also made it a point to distribute our book for newly diagnosed patients, an invaluable resource called *We Have Walked in Your Shoes*, to those who come to the group as newcomers, about to begin their cancer journey.

Tracy's Co-Facilitator, Courtney Bresler-Nowak, MSW, LSW shared these words with SPOHNC..."Tracy brings a strong background of experience and knowledge to her work with patients. I have observed her deep care and concern for individuals who are navigating the unique experience and challenges of head and neck cancer treatment. I'm grateful for Tracy's leadership and dedication to patients and families that we support."

Tracy's group had always supported each other in person, but with the challenges presented by Covid several years ago, the group stopped meeting in person after their meeting in March of 2020. They did not have formal meetings

of any kind for a while, but Tracy, as their dedicated and committed Facilitator, continued to check in with group attendees via email and phone calls for quite some time. The group then switched to a virtual platform of support in November of 2021, and has remained that way ever since. Tracy also referred several newly diagnosed patients to SPOHNC so they could find a volunteer to connect to through our National Survivor Volunteer Network. She is also always willing to welcome students/guests to the meeting, but not before being careful to get permission from the group. Tracy maintains the privacy of her group attendees to ensure that they always feel comfortable sharing within the circle.



Tracy is also always available to help us in the national SPOHNC office by providing information concerning dental health or other healthcare professionals when we are seeking help for patient callers.

Tracy furthers her facilitating skills by being a member of our closed SPOHNC Chapter Facilitators Facebook group. The group is kept up to date with SPOHNC's happenings, as well as sharing ideas and best practices amongst each other.

The SPOHNC Penn Philly support group meets virtually on the first Thursday of each month (except August), from 11 am to noon.

For all the things you continue to do in support of those who come to SPOHNC seeking information, inspiration and the camaraderie of others, we thank you, Tracy, so very much. You are loved and appreciated, today and every day, and it is our pleasure to honor you as SPOHNC's November Champion of Hope.

"Thank you SPOHNC,
for all you do."

~ Tom H.

Happy Birthday Dr. Myers!



SPOHNC would like to extend birthday wishes to someone who is very special to us. Eugene Myers, MD, FACS, FRCS Edin (Hon), a highly esteemed and much beloved member of our Board of Directors, celebrated a birthday this month, on November 27th. Happy Birthday, Dr. Myers!



We hope you celebrated with joy, in whatever way you wished to. We hope you have a year full of joy, laughter, and special times spent with family, friends and colleagues. SPOHNC celebrates you every day!!

Great Recipe for Added Calories



Baked Acorn Squash

Ingredients:

1 acorn squash	1 tsp. ground cinnamon
4 Tbsp. unsalted butter	1 tsp. vanilla extract
1 Tbsp. dark brown sugar	Pinch of ground cloves (optional) Pinch of salt

Directions:

<ol style="list-style-type: none"> 1. Preheat oven to 350. 2. Grease baking sheet & baking dish. 3. Halve the squash lengthwise. Transfer the squash, cut side down, to the baking sheet; bake the squash until tender, about 45 min. Don't turn off oven. 	<ol style="list-style-type: none"> 4. Melt butter & stir in the remaining ingredients. Keep the mixture warm until it's needed. 5. Arrange squash, cut sides up, in baking dish. 6. Spoon butter & seasonings equally over the sections. 7. Bake squash another 15 min, until soft. 8. Serve hot. Yields 2 (8 ounce) servings (approximate).
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Nutritional Facts: Calories 325(kcal), Total Fat 23(g), Saturated Fat 14(g), Cholesterol 62(mg), Sodium 79(mg), Carbohydrate 31(g), Dietary Fiber 4(g), Protein 2(g).

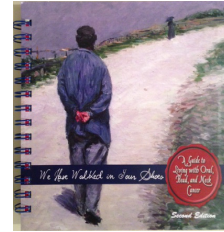


Check out our recipe book for more foods that soothe post-treatment discomfort!

SPOHNC's RESOURCES

A Guide to Living With Oral, Head and Neck Cancer

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



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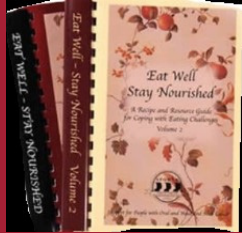
Eat Well Stay Nourished A Recipe and Resource Guide for Coping With Eating Challenges

compiled by
Nancy E. Leupold,
Founder

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Caregivers, We Salute You!

In November, gratitude is the recurring theme. Everywhere you go, you see images and ideas shared for expressing gratitude. Our gratitude journals are bursting with feelings and thoughts. November is also National Family Caregivers Month. Think about who is, or was, your caregiver along your cancer journey, and celebrate them in some special way this month, and always.

Our caregiver volunteers, and the caregivers who have contacted SPOHNC over time seeking help for their loved ones, deserve special recognition. What can you do to share gratitude for your caregiver today?

Our caregiver volunteers have shared some really important thoughts and lessons with SPOHNC, so we want to share them again, because it's important to remember, as a caregiver, that you matter too.



SPOHNC's National Survivor Volunteer Network caregiver volunteer, Connie Lunt, shared these thoughts with SPOHNC, several years ago...

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

H - *Have Patience - This is a learning process for you and the patient.*

E - *Everyone wants to know. Designate a spokesperson to share info and respond to calls, etc.*

R - *Read the book that is recommended (We Have Walked in Your Shoes). Available through SPOHNC.*

E - *Every patient has difficult moments. You might have to get tough and push them.*

F - *Friends and Family - It will take a Village - get yours in place and ask for support.*

O - *Open your mouth! Do not be afraid to ask! Any question is OK! Ask them to spell the big words!*

R - *Roles change - you will wear many "Hats"- some of them will be new to you!*

Y - *You need to take time for yourself - Breath - do something that makes you feel good.*

O - *One important phone call - SPOHNC! You and your patient can receive support!*

U - *Use your smile! Nurses and doctors will be your best friends. Treat them with respect and say thank you!*

Caregiver Tina Benscoter shared these thoughts with us as well...important things to remember – that helped her along the caregiver journey.

Ten Things (I wish I had known in March 2015):

1. Appreciate simple things. For example eating, swallowing, drinking water, tongue movement, speech, your airway etc. We tend to not give any of these even a passing thought; however, few things hit home harder than day after day of not being able to enjoy a simple, quiet, stress free meal with your spouse. The humanity of it is startlingly visceral and sad. I have never taken these things for granted again.
2. Seek an integrated medical team. They are literally and figuratively life savers. They will coordinate your care for you which allows you to proceed seamlessly from appointment to appointment and treatment to treatment. You won't have to schedule, make phonecalls or try to work through the medical system. Hopefully your medical team will also have an active tumor board to ensure continuity of treatment and care across medical specialties. Taking responsibility for all of the medical logistics away from me was the biggest relief.
3. Listen to your medical team but listen to your gut too. Don't hesitate to call the doctors, even after hours. You might save a life. Cancer doctors expect those after hours calls. Be an advocate and an aggressive one, if need be. Let 'better safe than sorry' be your mantra.
4. Do not let cancer isolate you. Family and friends will try mightily to help you and to understand. Unfortunately, or fortunately for them, they will never grasp what you are going through. Plus you might not be capable of articulating what

Honor your Caregiver

today

and always



you need. That means self care is a must for the patient and the caregiver. This ‘race’ is also marathon not a sprint. So take the meds, go for the counseling, find the SPOHNC support group... do what it takes to keep putting one foot in front of the other regardless of your role in the cancer fight.

5. Get a GI feeding tube. A feeding tube is a literal life saver. Reluctance is silly. Better to have it and not need it than vice versa. My husband lost 50 pounds, that he did not have to lose, WITH a GI feeding tube.

6. Dreading scans is normal and scanxiety is real. It is horrible every single time no matter where you are on the journey. I wish this were not true.

7. Staying in the present is critical. Even a small issue, real or imagined, may take you right back to the worst place in your life. This is one description of PTSD. There will be days that it will be nearly impossible to focus on one day at a time. Expect those days and know that they too shall pass.

8. Do not neglect yourself if you are a caregiver. You might feel forgotten. Caregiver burn out is real so make yourself take a respite break where ever you can even if it is just a quick cup of coffee with a friend or a visit to a favorite quiet spot alone for a few moments. The recharge will help you pick up your battle armor again and to fight on. Taking respite is not a selfish act.

9. Progressing through your treatment and recovery might not be linear. In fact, things might get worse before they get better. Expect setbacks and hiccups. They will pass.

10. Stop Googling and ask the professionals for their input. The internet does not know you. Truth and data always beats speculation, misinformation and shared on-line horror and ‘war’ stories. Nothing positive is gained from this type of on-line speculation about your situation.

Practicing self-care, as a caregiver, is one of the most important things you can do, both for yourself, and for your loved one. At all times, but especially during the holiday season, please be sure to remember that you are important, and what you need matters too.

We all love our caregivers, and we want them to feel good about what they do for us, while feeling like they can, and do, still take care of themselves. Celebrate the caregiver in your life, today and every day, because ***Together, WE Heal.***

Massachusetts Oncology Patients Survivors and Supporters On the Move

Jane, Amy and Tom attending the head and neck cancer symposium at BU promoting MOPSS (Massachusetts Oncology Patients, Survivors and Supporters). They will be heading to the state house soon to push for insurance coverage for people in Massachusetts who need medically related dental care.



Meeting with Massachusetts State Representative Paul McMurtry on October 14th at the State House. A big thank you to Representative McMurtry for sponsoring Bill 1094 and hosting the MOPSS crew, where they were also able to visit other legislators and advocate for Bill 1094. Let's make oral health a priority. Dental Care is Health Care!!!



An Important Message from MOPSS

MOPSS is working with elected representatives in Massachusetts, as well as the medical and dental community, to promote House Bill 1094. If this bill is approved, it will mandate insurance providers doing business in Massachusetts to cover medically related dental treatment. This initiative is especially critical for head and neck cancer survivors who have already endured significant challenges, such as radiation therapy. Your invaluable contributions can help us underscore the significance of this legislation and convey to key stakeholders why their backing is indispensable. Sharing your story and insights can help us drive home the importance of this legislation and demonstrate to these key stakeholders why their support is crucial.

The dedicated MOPSS committee has been tirelessly working towards this objective for numerous years, and we now urgently require your assistance!

We would like to stress that your time commitment is entirely flexible and designed to accommodate your schedule and availability. If you're interested in joining us for our

next Zoom meeting, kindly express your interest, and we will promptly send you an invitation to our upcoming session.

If you live in Massachusetts and would like further information about upcoming meetings and how you can volunteer, please contact the MOPSS committee at mopssma@gmail.com or call us at 781-686-3774.

You can make a difference - please volunteer! THANK YOU for considering this critical cause.

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, Beth Israel Lahey Health, Boston Medical Center and the Massachusetts Dental Society. The list of supporters, institutions and organizations continues to grow as MOPSS outreach continues!

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

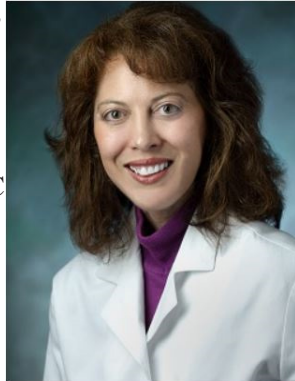
News from the Board Room

Karen M. Ulmer, MSN, RN, CORLN

It is with great pleasure that we announce a new member of SPOHNC's Board of Directors. Welcome, Karen M. Ulmer, MSN, RN, CORLN!

Karen was brought to our Board by Dorothy Gold, fellow Board member, and former Facilitator of the SPOHNC Baltimore, MD Chapter at The Milton J Dance Jr. Head and Neck Center at Greater Baltimore Medical Center.

Karen is a member of SOHN and ONS, and is certified in Otorhinolaryngology, Head-Neck Nursing (CORLN) care. Karen brings a unique



perspective to our Board of Directors through her 20+ years of experience working with head and neck oncology patients and their families and friends. She enjoys helping patients achieve their individual goals during and after therapy.

Karen has expertise in the management of tracheostomies. She is available for inpatient and outpatient tracheostomy consultations. She is also a member of the Oncology Nursing Society and is active in the Society of Otorhinolaryngology and Head-Neck Nurses on both the local and national levels.

We look forward to working with Karen, and to welcoming her to our esteemed group of head and neck cancer healthcare professionals. Thank you for joining our SPOHNC family.



Survivor News



It wouldn't be the Fall semester without Frank Marcovitz' annual visit to Barbra Lederer's graduate speech pathologist program at Hofstra University in Uniondale, NY. Frank has been a regular guest speaker in the class for the last 10 years!

His visit gives the graduate students real world knowledge of what it's like for someone who is living with a laryngectomy. If anyone is perfect for this assignment, it's Frank. He has always

said he doesn't let his cancer define him. He inspires so many with his zest for life!

Thank you Frank, for all you do to help raise awareness and help students, and support patients as well. SPOHNC is grateful!

Do you have news to share?

Special occasions should be celebrated, so send us your news!



We want to shout it from the rooftops!

Send it to info@spohnc.org

In Memoriam - Lewis J. Beilman

Our hearts are broken, as we share with you the very sad news of the passing of one of our dearest SPOHNC family members. Lewis James Beilman Jr. passed away on Oct. 14, 2023, in Palm Coast, Fla.

Lewis was born in Middletown, CT on Feb. 19, 1944. His family moved from Connecticut to Florida when he was a teenager. He graduated from Miami Jackson Senior High School in 1962. After high school, Lewis served in the U.S. Navy during the Vietnam War. He was part of the Navy's Nuclear Power Program and later assisted with operating the nuclear reactors on the U.S.S. Enterprise. He also played trumpet in the Navy band.

Lewis put himself through college after his military service and graduated from Florida International University. Post-college, he spent most of his 30-year professional career as a financial controller at Combustion Engineering (CE) and Asea Brown Boveri (ABB). He and Amy retired to Palm Coast, Fla., in 2006.



In 2011, Sandy Walker connected with SPOHNC. She called to find out what kind of support services we could offer to her dear friends, Amy and Lewis Beilman. Lewis had just been diagnosed, and Amy needed help. She was not prepared for the caregiver role she was about to take on. Lewis had been diagnosed with tonsil cancer, and treatment began.

After being matched with a survivor volunteer for Lewis, and a caregiver match for Amy, the Beilman's began their cancer journey, and their relationship with SPOHNC. From support, to friendship and beyond, this amazing couple has given back to so many in so many ways, and they remained steadfast in their support of those who travel the head and neck cancer journey.

A bond was created that only strengthened over time, as the Beilman's became a truly integral part of our SPOHNC family. They even visited

our office here in NY on a drive up north to visit family, along with their beloved fur baby, Hero. It was a day, and a visit, that we will always hold dear.

For more than 8 years, Lewis and Amy gave so much of themselves as they supported others along the head and neck cancer journey. They volunteered and facilitated the Palm Coast Northeast, FL SPOHNC Chapter support group, and they continued to lead Move to Music, an exercise class which started in 2008. Lewis always took special care to create amazing and inspiring playlists for the class, many of which are still used today. The class held one special fundraiser each year, where they raised funds and donated them to SPOHNC. Through the class, raffles, and silent auction items, the Beilman's surpassed their fundraising goals every year. It was something that the Grand Haven community looked forward to, as they came together to support each other, and SPOHNC. The time and effort that this amazing couple put in to support SPOHNC was truly unmatched and will remain in our hearts forever. Each year, the event grew larger and larger, and the support of their friends never wavered, just like the support that Amy and Lewis continued to offer to everyone within their SPOHNC Palm Coast family.

Lewis' love of animals was apparent as he spent several years as President of the Flagler Humane Society. Hero was Amy and Lewis' devoted and loving fur baby, and was always very close with Lewis. Lewis also loved to remain active, even outside of Move to Music. He loved tennis and biking, and walking Hero as well.

Beautiful tributes to Lewis have been pouring in to SPOHNC. It's plain to see just how very much he was loved within the community, their support group and beyond.

Ron and Sandy Walker shared these thoughts with SPOHNC...
"Lewis was a special guy who devoted so much time and energy to others who had a similar cancer"

Mr. & Mrs. David Hall sent a note to SPOHNC...
"He displayed such courage and strength. We will miss him. Our deepest Sympathy"

Mr. & Mrs. Reisman shared these words...
"Lewis was an inspiration to all."

Mrs. Joan Scheerer said *"He was the best!"*

SPOHNC's Executive Director, Mary Ann Caputo, shared her heartfelt sentiments, on behalf of the SPOHNC family... *"our hearts are broken. Lewis was a beautiful soul who we admired, and he will be missed by many. And to our dear Amy... We have met a number of special people through SPOHNC yet the two of you went beyond our expectation of friendship, caring and love. We love you and will keep you in our thoughts and prayers."*

Lewis will always be remembered for his broad smile, his positive attitude, and his love of life.

He was always up on the "news of the day" and remained interested in the fate of the Miami Dolphins through his last days.

Lewis remained an inspiration to so many during his more than 12-year journey. No matter what difficulties life showed to him, he made the best of each day and was grateful for whatever time he had with his family, friends, and animal companions.

We will miss our dear friend Lewis and hold him in our hearts forever. Amy...our hearts are broken for the loss of your love. We remain here for you for whatever you need. Keep marching, dear friend. We love you...



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~ Leanne

Head and Neck Cancer News

Yoga-based intervention benefits patients with head and neck cancer

A yoga-based intervention provided beneficial supportive care among a cohort of patients undergoing radiotherapy for head and neck cancer and their caregivers, according to study results.

The findings — presented during ASCO Quality Care Symposium — specifically showed improvements in physical function and nutrition intake among those assigned the yoga-based intervention vs. those assigned usual care.

Rationale and methods

“The idea with descriptive studies is to help figure out how to best support patients and their families and what type of intervention may be best for the problems that they’re dealing with,” Kathrin Milbury, PhD, associate professor of behavioral science at The University of Texas MD Anderson Cancer Center, told Healio.

“From a supportive care perspective, head and neck cancer hasn’t been that widely studied,” she added. “I have noticed that the physical symptom burden of this type of cancer is very distressing and so just addressing the distress without the physical symptoms wouldn’t be as effective, and that is where the yoga intervention comes in because it addresses both mind and body.”

Researchers assigned 100 patients (mean age, 60.3 years; 85% men; 79% white; 67% early-stage disease) with head and neck cancer undergoing radiotherapy to one of three groups: dyadic yoga-based supportive care intervention (n = 34), patient yoga-based intervention (n = 33) or usual care (n = 33). Both yoga programs included 15 in-person or videoconferencing sessions in parallel with radiotherapy treatment and consisted of poses that focused on preventing and reducing common side effects of head and neck cancer treatment. Techniques included stretching and strengthening the neck and facial muscles, whole-body postures to prevent muscle loss, and breathing and meditation exercises to create a relaxed state and sense of wellbeing.

Of note, patients frequently experience anxiety during radiation treatment and some patients who participated in this trial used the relaxation exercises during treatments in lieu of benzodiazepines, according to the researchers.

Findings

Investigators found that 88% of patients assigned the two yoga groups attended at least 10 yoga sessions (mean, 13.1 sessions in the patient-caregiver group vs. 13.3 sessions in the patient group). Results showed a significant effect on patient-reported physical function (F = 5.27; P = .03) and nutrition intake (F = 4.97; P = .03) favoring the patient-caregiver yoga group compared with the usual care group. Researchers also found that patients in both the dyadic (P = .05) and patient-based (P = .02) yoga groups experienced significantly fewer feeding tubes placed compared with those in the usual care group.

Future research

These results demonstrate that a focused yoga intervention can be successfully delivered in person or online not only to patients with cancer undergoing radiation therapy but also to their caregivers,” Charu Aggarwal, MD, MPH, FASCO, assistant professor for lung cancer excellence at University of Pennsylvania’s Perelman School of Medicine and Healio | HemOnc Today Editorial Board member — who was not involved with the study — said in the ASCO release. “Such an intervention can be beneficial for physical functioning, recovery and nutrition intake.”

The researchers are currently studying the dyadic yoga intervention for patients with head and neck cancers undergoing concurrent chemoradiation that evaluates use of feeding tubes and ER visits as primary outcomes. They also plan to test the acceptability of this intervention among historically underserved populations, according to an ASCO press release.

“Patients should engage in relaxation techniques because it is very important. We would love for patients to practice yoga that focuses on areas in the neck region, the jaw and facial muscles, because exercising the neck and facial areas reduces lymphedema, which is associated with swallowing difficulties,” Milbury told Healio. “We are hoping to make an exercise intervention — such as yoga — part of standard of care for these patients. That is our long-term hope, but we still need to complete confirmatory work. We are also performing cost effectiveness analyses with a health economist that will hopefully help us to show the cost benefit of this type of intervention so that we can have enough data to support implementing it as part of usual care.”

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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 SPOHNC to find out more.



Featured above is SPOHNC's Minneapolis, MN Chapter Support Group

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

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