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A PROGRAM OF SUPPORT
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PEOPLE WITH
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Hearing Loss in Head and Neck Cancer Survivors

Nicole C. Schmitt, MD¹ and
Katharine Fernandez, AuD, PhD²

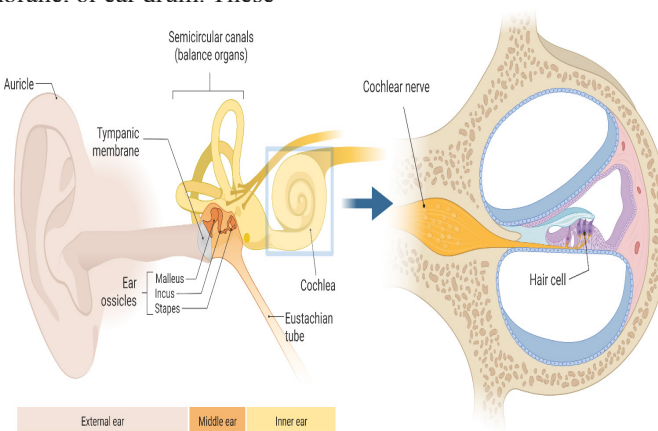
Projections based on International Agency for Research on Cancer (IARC) 2020 estimates predict a 14.7% increase in new head and neck cancer cases by 2030 due to the growth and aging of the global population. Therefore, a focus on quality of life after therapy is now more important than ever. Hearing loss is a relatively common side effect of therapy used to treated head and neck cancer. In this article, we review the causes and management of hearing loss in head and neck cancer survivors.

Inner Workings of the Ear

The ear consists of three parts: the external ear, middle ear, and inner ear. The external ear is the part of the ear that we can see and touch and consists of the auricle (or pinna) and the ear canal. The auricle's job is to funnel sounds from the environment through the ear canal to vibrate the tympanic membrane, or ear drum. These vibrations are carried and amplified by three tiny ear ossicles (bones) in the middle ear. The mechanical vibrations of the ossicles then set into motion the fluid-filled compartments within the hearing organ, known as the cochlea, within the inner ear.

Figure 1: Anatomy of the ear. Created with Biorender.com, with permission.

The cochlea is a small, snail-shaped organ containing thousands of sensory cells called hair cells, which



have hair-like protrusions called stereocilia to detect sound waves that are transmitted through the cochlea. Different regions of the cochlea response to different pitches of sound, much like keys on a piano. The hair cells at the base, or bottom of the cochlea, transmit high-pitched sounds, while the cells at the apex, or top of the cochlea, transmit lower-pitched sounds. Any movement detected by these cells through fluid displacement in the cochlea is transduced to an electrical, nerve impulse that is transmitted by the auditory nerve to the brain where it can be interpreted as sound. However, these hair cells, particularly those in the outer rows, are very sensitive to damage caused by noise exposure, aging, and exposure to toxic drugs. Once damaged, these hair cells cannot be replaced.

How Does Treatment for Head and Neck Cancer Cause Hearing Loss?

Chemotherapy is a drug-based treatment that uses chemicals to kill growing cancer cells. Cisplatin is a widely used and effective anti-cancer drug that is often a critical component of chemotherapy. However, cisplatin is also toxic to the ear. Cisplatin accumulates in the inner ear, where it can damage the auditory hair cells, nerve cells, and other parts of the cochlea. Its effects on hearing can be severe and are permanent. The timing and magnitude of hearing loss is variable and often related to the dose; that is, the higher the cumulative dose, the greater the damage to the ear. The duration of therapy and exposure to other toxic chemicals may also influence an individual's susceptibility to hearing loss. Hearing loss has also been reported with carboplatin, a similar drug, though the frequency and severity of hearing loss may be reduced relative to cisplatin. Some oncologists use this drug as an alternative to cisplatin in patients who have pre-existing hearing loss.

Radiation therapy is often coupled with chemotherapy. Radiotherapy uses high doses of radiation to kill cancer cells and shrink tumors. With modern radiation techniques used

for cancer of the mouth or throat, the doses of radiation that reach the cochlea are usually low enough to avoid significant damage. However, radiation delivered to cancers located near the ear, such as cancer involving the sinuses or parotid salivary gland, may result in doses to the cochlea that may be high enough to cause damage to the inner ear, resulting in permanent hearing loss. More commonly, radiation can

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cause inflammation of the middle ear lining, causing fluid buildup and muffled hearing, which is often temporary.

What Kinds of Hearing Loss are Caused by Head and Neck Cancer Treatment?

Hearing loss caused by fluid buildup in the middle ear is called conductive hearing loss, which interferes with the ability of the middle ear to transmit sound vibrations effectively to the cochlea. This type of hearing loss will cause all sources of sound to seem muffled or muted. This is relatively common after radiation therapy but often temporary, resolving on its own within a few months. In some cases, it can be a long-term condition.

For reasons that are not completely clear, the hair cells at the base of the cochlea are more susceptible to damage from cisplatin chemotherapy. As a result, hearing loss from head and neck cancer treatment most often affects the higher pitch frequencies. Over time and with continued exposure to drug treatment, the damage can extend to lower frequencies that are more commonly associated with human speech. Patients who have experienced this type of hearing



loss tend to notice increased difficulty hearing higher-pitched voices and difficulty making out words when there is a lot of competitive background noise. This can lead to frustration and social isolation. Some people appear to be more susceptible than others to this type of hearing loss. Factors such as age, gender, genetic susceptibility, other underlying medical conditions, smoking, diet, exercise, stress, and pre-existing hearing loss all play a role in the risk for development of hearing loss. Specifically, we have found that very young patients, older patients, and patients with better hearing at the beginning of their cancer treatment are more likely to notice a negative change in hearing afterward cancer therapy. Awareness of these risk factors may help your medical team determine optimal treatment approaches.

Independent of the perception of new hearing loss, individuals also may notice new or worsening tinnitus, which is a constant ringing, buzzing, or tone in one or both ears. Tinnitus may be soft or loud, high pitch or low pitch. It may be perceived in only one ear or both and can be constant or come and go. It is not harmful or dangerous but can be distracting to the extent that it may interfere with daily routines.

How is Hearing Loss Diagnosed?

Hearing loss can be evaluated and diagnosed using pure tone audiometry. This test is usually done in a sound-proof booth by a licensed audiologist. Hearing capacity is assessed by presenting a series of sounds at different pitches and volumes through a set of headphones, taking note of what you can hear. Any decline in hearing capacity below the normal range of hearing is referred to as a hearing loss, which can range in severity from mild to complete (Table 1). Your audiologist will review the results with you. If a hearing loss is detected, they can advise you on the best way to move forward. It is also a good idea to check in with your ear, nose, and throat doctor to make sure there is no other underlying problem that could be contributing to hearing loss.

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Table 1. Severity of hearing loss and associated impact on listening environment

Grade	Hearing in a quiet environment	Hearing in a noisy environment
Normal hearing	No difficulty hearing	No or minimal difficulty hearing
Mild hearing loss	No difficulty hearing conversations	May experience problems hearing conversations
Moderate hearing loss	Difficult to hear conversation unless voices are raised	Difficult to participate in conversation
Severe hearing loss	Cannot hear conversations and may struggle to understand raised voices	Difficult to hear most speech and participate in conversation
Profound hearing loss	Increasingly difficult to hear raised voices	Increasingly difficult to participate in conversation
Complete/total hearing loss/deafness	Cannot hear speech and most sounds in surrounding environment	Cannot hear conversations or sounds in surrounding environment
Unilateral	May not experience difficulty unless sound is near the ear with hearing loss; may struggle to localize the sound source	May experience difficulty hearing and participating in conversation; may struggle to localize the sound source

What Treatment is Available?

Hearing loss that damages the inner ear – as a result of chemotherapy and/or radiation – tends to be permanent. Although much research is underway to find ways to help sensory hair cells regenerate, right now there are no proven ways to restore hair cells once they are damaged. If a drug-induced hearing loss causes problems with communication, an audiologist will recommend aural rehabilitation. Aural rehabilitation ideally should precede cisplatin chemotherapy. During such sessions, techniques including speech reading and compensatory communication strategies are introduced to the patient and to family members. Hearing loss may place a burden on more than just the person with cancer but their communication partners too.

Benefit may also be gained from the use of assistive listening devices such as hearing aids, cochlear implants, and FM amplification devices. Hearing aids are small electronic devices that you wear in or behind your ear. They work by intensifying sound vibrations entering the ear making it easier for a damaged cochlea to detect and interpret sound. There are practical limitations to the amount of amplification from a hearing aid. Individuals with severe to profound hearing loss may be better suited for a cochlear implant. In this case, a small electronic



device, consisting of an external portion that sits behind your ear and an internal portion that is surgically implanted under the skin, transmits signals directly to the auditory nerve, bypassing the damaged cochlea. A licensed audiologist can help you determine your candidacy for hearing aids or a cochlear implant based on your hearing test. An ear, nose, and throat surgeon will rule out any other medical causes of hearing loss and clear you to be fitted for either technology.

There is no established medical treatment for tinnitus but there are treatments that may help people cope with the condition. Wearable sound generators or tabletop sound generators that emit soft white noise, music, or other pleasant sounds may help to mask the tinnitus. Counseling or tinnitus retraining therapy approaches focus on education to help change the way you think or react to tinnitus so that it is less bothersome.

Can Hearing Loss Be Prevented?

This is an exciting area of research. After decades of studying different drugs in animals and humans, several medications and supplements are now in clinical trials for prevention of hearing loss in head and neck cancer patients receiving cisplatin chemotherapy and radiation. However, there is currently no proven or FDA-approved strategy for preventing hearing loss from

cisplatin chemotherapy in adults.

Because most hearing loss caused by damage to the inner ear cannot be restored, it is also important to avoid further damage by avoiding activities that could result in head trauma and exposure to noise. Common household items such as headphones and lawnmowers can be surprisingly loud, causing damage when used over long periods of time. It is important to wear ear plugs or other protective devices when you are in a loud setting for more than a few minutes.

Impact of Untreated Hearing Loss

If left unaddressed, hearing loss can greatly reduce the overall quality of life of cancer survivors. Living with hearing loss runs the risk of impeding daily communication, cognition, education, employment, mental health, and interpersonal relationships. Hearing loss is associated with low self-esteem and depression. For these reasons, it is important that we stay ahead of the problem. The aim of ototoxicity monitoring programs is to detect hearing loss early, before it spreads to areas of the cochlea that can impede daily communication. As mentioned earlier, cisplatin-induced hearing loss first targets regions of the cochlea that are devoted to high pitches, pitches higher than even those involved in speech. Using optimized auditory testing, audiologists can monitor changes in this high pitch range to identify a hearing loss before it presents as a problem to daily communication. For this to be effective, a hearing test will be administered prior to cisplatin chemotherapy to serve as reference baseline. Additional tests will be collected prior to each additional drug administration. Any concerning amount of change should then be discussed with the medical team to respond appropriately. In some cases, an adjustment to the chemotherapy regimen may be possible to reduce further ototoxicity. In other cases, counseling and amplification options will be explored to reduce the impact of hearing loss on the individual.

Summary

Hearing loss is a relatively common and frustrating side effect among head and neck cancer survivors. Although in most cases hearing cannot be restored, the use of hearing aids and FM devices can be helpful. There is active research on strategies for
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preventing loss, which may help future head and neck cancer patients.

Where Can I Get More Information?

Please mention any hearing-related symptoms to your doctor or audiologist, who can help with diagnosis and treatment. Here are some useful websites:

- <https://www.nidcd.nih.gov/health/hearing-ear-infections-deafness>
- <https://www.asha.org/public/hearing/hearing-loss/>
- <https://www.cdc.gov/ncbddd/hearingloss/types.html>

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Dubno JR, Newlands S, Schmitt NC, Cunningham LL. Atorvastatin is associated with reduced cisplatin-induced hearing loss. *J Clin Invest* 2021;131:e142626.

Editor's Note: Nicole C. Schmitt, MD, is a head and neck surgeon-scientist and Associate Professor at Winship Cancer Institute of Emory University. She completed residency at the University of Washington and head and neck surgical oncology fellowship at the University of Pittsburgh. Dr. Schmitt's research interests include immune aspects of novel therapeutic combinations for head and neck cancer and patient survivorship concerns, including hearing loss.

Katharine Fernandez, Au.D. & Ph.D., is a clinician/staff scientist at the National Institute on Deafness and Other Communication Disorders (NIDCD) at the National Institutes of Health in Bethesda, MD. Dr. Fernandez completed her doctoral work at James Madison University before completing a post-doctoral fellowship at Harvard Medical School at the Massachusetts Eye and Ear Infirmary. Her research interests include noise- and drug-induced hearing loss with an emphasis on guiding otoprotection studies. Currently, Dr. Fernandez is developing animal models to appropriately study cisplatin ototoxicity and conducting clinical studies in head and neck cancer patients to explore potential otoprotectants.

“35”

Katie Drablos presents... “35: a celebration of being alive.” On 2/19/21, Katie went to an ENT with what she thought was a canker sore and walked out a 33 year old, single, non-smoking, New Yorker with tongue cancer. Scans, surgeries, radiation, chemotherapy and a whole lot of nasty side effects followed, some that still haunt her today, but she's here. And she's so damn grateful to be lucky enough to be here, keeping the cancer beast at bay.

On 4/1, Katie turns 35 and will house two shows at Arts on Site, 12 St. Mark's Place, NY, NY, 10003, at 6:30 and 8:30 pm. This dance narrative show shares some of Katie's stories; how she found solace and the strength to press on through music, people,

and the healing power of dancing. She owes immeasurable thanks to the human beings, especially fellow cancer warriors, who paved the way for how to fight with grace, even when the battle is not likely won.

Tickets are \$35 and all proceeds benefit SPOHNC. Please note that masks and proof of vaccination are required for this theater.

Link for tickets: <https://artsonsite.ticketleap.com/studio-3r-performances/details>

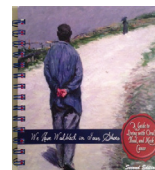
If you are unable to attend the show in person, please consider making a donation to SPOHNC at <https://www.spoehnc.org/donate-to-spoehnc/>. If you wish you can select a donation type, pick honorarium and type in Katie Drablos.

With big love,
Katie Drablos



Editor's Note: In the February 2022 issue of “News from SPOHNC” (Volume 31, No. 5), there is a correction to the feature article entitled *The Use of Hyperbaric Oxygen Therapy in Head and Neck Cancer Patients* by Ziad K. Mirza, MD, CPE, CMD, FACP, MBA, ABIM, ABPM/UHM on page 2. The sentence: “This prophylactic treatment with hyperbaric oxygen therapy, as a modality to prevent ORN, is used by 78% of hyperbaric providers in the United States today, although all insurance companies do not cover it.” should have read: “This prophylactic treatment with hyperbaric oxygen therapy, as a modality to prevent ORN, is used by 78% of hyperbaric providers in the United States today, although some insurance companies may not cover it.” Our apologies for any misunderstanding this may have caused.

SPOHNC's most popular resource for newly diagnosed patients...



**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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April Awareness is Just Around the Corner!

What Are You Doing in April?

As we all know, April is Oral, Head and Neck Cancer Awareness Month. This is in recognition of the month that SPOHNC's founder, Nancy Leupold, was diagnosed with oral cancer, more than 31 years ago. For the past few years, SPOHNC has been raising awareness, along with our Chapters, newly diagnosed patients survivors and caregivers in unique ways. There were events, screenings, walks, runs, bake and garage sales and so much more. The pandemic changed all of that, and so many events were cancelled. With the last 2 years behind us, let's all work together to raise awareness.



As things begin to slowly open up across the country, we have heard about some events that are coming in April. Do you have

something to share? Tell us how you are raising awareness of oral, head and neck cancer. Send us your stories and pictures, to info@spohnc.org, for inclusion in social media posts and in our newsletter. We want to hear from you!

In doing our part from the national office, SPOHNC has been busy connecting with cities and states across the country where we have SPOHNC Chapter support groups. We are asking unique venues in those cities and states to raise awareness by joining our 2022 SPOHNC Illumination Family. Buildings, water towers, bridges and other unique venues will be illuminated in the colors of SPOHNC, at some point in April, to raise

awareness of oral, head and neck cancer. This program has been successful in past years and we are hoping to expand our Illumination Family even more in 2022!

Be on the lookout in your inbox, on social media and in future issues of our newsletter, for posts, pictures and stories about these illuminations. Check out our "Illumination Calendar" and if you are nearby to any location that is part of our Illumination Family, snap some pix on your phone and send them to SPOHNC! If you know of a building or venue that lights



up to raise awareness for causes throughout the year, let us know at SPOHNC and we will connect with them to join our Illumination Family. Help us to raise awareness across the country, in your city, town, community or neighborhood.

How Can I Raise Awareness?

Do you like the idea of helping to raise awareness of oral, head and neck cancer, but you're not sure how? Here are some ideas for you...

Wear It

Wear burgundy and ivory on Monday's, Friday's or whenever you would like to. Keep it consistent, so people will start asking you why.

Raise Funds

Not everyone has the ability to do this, but if you can come up with a creative way to raise funds for SPOHNC so we can continue to expand our programs and services of support, go for it!

Donate

Can't do a fundraiser? Donate to SPOHNC and encourage friends and family to do the same.

Volunteer and Participate

Become a National Survivor Volunteer Network survivor or caregiver volunteer,

or join a SPOHNC Chapter support group meeting.

Talk About It Online

Social media is a powerful tool for raising awareness. Share it on Facebook and Instagram. SPOHNC will be posting almost daily, so you have ready-made content to share.

Research

Learn more about SPOHNC and tell your healthcare professionals about us. Help

support future patients and survivors this way.

Recruit

If you meet others who are beginning their cancer journey, share SPOHNC with them, so they know they are not alone, because Together WE Heal.

Talk to Your Government Officials

Share SPOHNC and oral, head and neck

cancer awareness with them, which may help in raising awareness of the issues surrounding survivorship and side effects, like dental issues and Medicare/insurance coverage.

Share Your Story

Share your cancer journey by writing about it for a upcoming issue of "News from SPOHNC." Call SPOHNC at 1-800-377-0928 or email us at info@spohnc.org.

Oral, Head & Neck
Cancer Awareness Month
— APRIL —



"Like" SPOHNC on Facebook

Time For Sharing...I Am Grateful

In the spring of 1993 I found a swelling just below my right jawbone. I assumed that it was an abscess and saw my dentist. He took one look and sent me to dental specialists who saw me the next day. They believed that it was more serious and recommended a surgeon at Beth Israel. I soon had scans and a biopsy which revealed that I had squamous cell carcinoma in the region of my tonsils. The surgeon recommended a radical neck dissection and it was scheduled for three weeks later. This was my first cancer terror. I had an image of cancer cells rapidly dividing and spreading tentacles all over. I believed I was safely in the care of an excellent surgeon during the day, but in the middle of the night, not so much.

The surgery was on Monday, June 7th. I remember little of the recovery and settled in for my expected one week stay. I hoped that my stay could be shortened as my daughter's 6th birthday was on Friday. It was deemed that if I could walk reliably and successfully navigate going to the bathroom, I could be sent home that Friday. It was uplifting for me and a huge surprise for Julie when she found me waiting to pick her up from school.

Several weeks later radiation at a local hospital began. A mask was made to hold my head immobile, bolted to the table during radiation. My face was painted in many lines of multicolor watercolor paint mapping (picture a subway map) the path of treatment. I could not allow my face to get wet. It all went easy until a few weeks later I discovered that I could not easily swallow food and soon after couldn't painlessly swallow anything. I lived on about 700 calories a day for several months, forcing myself to swallow a malted and a couple of glasses of water a day. I had already gone back to work for about five hours a day.

I was miserable, in terrible pain. The radiation oncologist was vague about how long the treatments would last. I was advised that pain killers would not help. I endured for 6 weeks, 4 days a week, then a week off, then another 6 weeks of treatment. My big treats were having my hair shampooed

at a hair salon (to keep my face paint dry), pure pleasure!

Several weeks after treatment I tried eating again. Smoked salmon, custards, ice cream, etc. I could no longer swallow dry foods as I produced very little saliva. I had lost seventy pounds. Before surgery I was terribly overweight and I drank more than I should. I had my last drink before the surgery and haven't had one since. To the extent that I could manage I tried to eat as healthily as possible, mostly soft, mushy and moist.

At a routine follow up with my surgeon Dr. Bloom, he did not like the look of a lump



he found at the site of my original lump. He wanted to do a biopsy. I asked when we could schedule it. When he said tomorrow, I had my first post surgery scare. The biopsy was negative; radiation had hardened the fat in my (double) chin.

I had already had some dental issues and started to experience round the clock dental pain. After months of fillings and gum treatments it was deemed that I should have my teeth removed. In order to allow for safe extraction and rapid healing, I was to undergo 10 hyperbaric oxygen treatments, then surgery, then ten more hyperbaric "dives." The surgery lasted a few hours, during which time it was discovered that my jawbone was infected and a good deal of it was scraped away.

During one of the high pressure dives my left ear became unable to equalize the pressure and blood and pain followed. My left Eustachian tube was no longer up to the task, so I had to see an ear doctor for laser punctures of my ear drums. The punctures were effective, but they were rapidly healed by the hyperbaric treatment so I had to have seven laser punctures.

I had been working for this entire period. It was embarrassing to be in public, even speaking in public without teeth. The healing and denture fitting took nearly 6 months. Because of the removal of a layer of jawbone, there was no longer a sufficient gum ridge on the left side to securely hold my lower dentures, making biting impossible and chewing problematic.

About ten years passed when I started to experience a tiny numb spot below my lip. When I realized it was spreading I saw a neurologist. After a couple of months of testing I was sent to a specialist to ascertain what could be done for what was described as radionecrosis. Several months later I was told, "I'm happy to tell you that you don't have cancer!" When I told that doctor that I was upset that he ignored the reason I saw him, he was surprised by my reaction. The numbness now encompasses my lower lip to down below my chin and most of the left side of my head.

In 2003 I was deemed to be cured. I lived a "normal" life, continued sobriety, learned how to eat healthier and also mushier. Except for nighttime panics ("what was that pain, what is that spot?" etc.) I was living my life. In 2012, I experienced a sore spot at the juncture of the left tongue and cheek. It seemed to go away. After some time I became aware of its return. I did not notice it because it was in a numb spot. I saw an ENT who did a biopsy which tested positive and he recommended that I see Dr. Teng at Mount Sinai. While showering me with empathy she explained the procedure I would be facing. For the surgery I would need a tracheotomy. My throat would once again be cut open from ear to ear. The left half of my tongue was removed and replaced using a 1.5 x 3 inch oval flap from my wrist. My wrist was repaired with a graft from my thigh. A feeding tube was inserted in my stomach.

I woke up on a ventilator which was soon removed. I was not to eat or drink at all. I had a cast from wrist to elbow to protect my wrist. At first I could not even lift it. I was visited by an army of residents and interns who made my new tongue bleed several times to ensure that there was good blood flow. I actually looked forward to that procedure which provided me with scant drops of fluid. Three days later I was home.

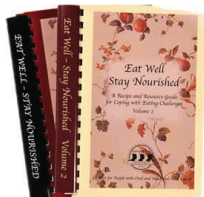
I had a visiting nurse for a few weeks who tended to cleaning and bandaging surgery sites. I ate and drank nothing with my mouth for about two months, during which time I returned to work full time. I was on a fluids diet through the stomach tube. My neck, so heavily radiated in the past, healed slowly. I saw Dr. Teng for evaluation of my

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

*compiled by Nancy E. Leupold,
Founder, in memoriam*

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**Marvelous March Recipes from
“Eat Well Stay Nourished A Recipe and Resource Guide
For Coping With Eating Challenges”**

Compiled and Edited by Nancy E. Leupold, Founder, in memoriam

Linda F's Fabulous Broccoli Cheese Soup (from Volume One)

2 to 3 medium-large stalks fresh broccoli chopped fine
½ c. finely chopped onion
½ c. finely diced carrots
½ c. finely diced celery
¼ c. butter
½ c. flour
1 qt. half and half
4 c. chicken broth
Dash of salt
Dash of paprika
1 c. cubed Cheddar or American cheese



Chop broccoli, celery, carrots and onion in a food processor or chop very fine. Bring broth to a boil in pot and add vegetables, except onions. Return to a boil and simmer 15 minutes. In a 5 qt. pot, melt butter and add onion, cooking until tender. Blend in flour, stirring constantly until smooth. Add half and half. Add ingredients from broccoli pot. Cook and stir until thick and bubbly. Lower heat; add cheese. Yields 8 (8 oz) servings. 392 calories/serving.

~ Linda F., VA



Key Lime Pie (from Volume Two)

1 graham cracker pie crust
1 (4 serving size) pkg. sugar free lime flavor gelatin
½ c. boiling water
2 (6 oz) Key lime pie flavor light yogurt
1 (8 oz.) fat free Cool Whip, thawed



Dissolve gelatin in boiling water. Cool. Stir in yogurt with a wire whisk. Fold in Cool Whip with a wooden spoon. Spread into crust. Refrigerate at least 2 hours.

Note: Any flavor gelatin and yogurt works – strawberry, peach, cherry etc.
Serves 8. 224 calories/serving

~ Sister Mary Ryan, IN, in memoriam



continued from page 6

ability to swallow. I could not swallow water without choking or coughing, which was frightening, but I could reasonably swallow thick fluids. For several weeks I progressed from shakes to purées to actual (soft) food and my feeding tube was removed. And once again I resumed living my life.

I was 62 then and when I became 65 and qualified for Medicare I retired. There was a scare due to a terrible sore throat, but biopsy was clear and what turned out to be an ulcer was treated. I felt pretty good, getting healthier, walking about 3.5 miles a day, and I started to think that I might just live for a while. I decided to invest in long needed, long awaited hearing aids. For a year I had recurring ear infections in my left ear which seemed to be healed with antibiotics, but oozing persisted. I saw another ENT.

One biopsy later, in 2019, it was determined that I had ear cancer. The procedure would involve removing my left ear. I saw Dr. Teng and her associate, Dr. Perez, an ear specialist for second opinions

and their procedure would allow me to keep the ear. Surgery for my third squamous cell carcinoma was another marathon event. My ear was lifted up but still attached and my ear canal, some middle ear, some bone and other tissue removed. My ear was reattached then sealed with some fatty skin from my belly, which was in ample supply despite now weighing 80 pounds less than I did in 1993.

I was scheduled for radiation 5 days a week for about 6 weeks and chemotherapy every Tuesday. The radiation was proton therapy at the New York Proton Center which was not remotely as harsh as the gamma rays 28 years earlier. Chemo was nothing, a piece of cake...until it wasn't. During the third week I developed difficulty eating and drinking, struggled with constipation and dizziness. After 5 weeks my red and white blood cell, platelets and hemoglobin were too low to continue with chemo. I finished the proton therapy, 100 pounds lighter than 1993 and slowly returned to "normal", the new normal of living in a pandemic.

I am grateful to two heroes, Dr. Bloom and Dr. Teng who must be named and all of the other doctors and health care professionals, too numerous to name who saved my life over and over again. I am grateful to my cousin Rita, a retired RN, who helped me evaluate medical advice and helped me when I panicked. I am especially grateful to my wife, Sarah, who has carried me and lived through all of this with me and my daughter Julie; those who care for us suffer with us too.

~ Allen Zimmerman
azimmerman1307@gmail.com



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

NEW
LOOK

As you may have noticed by now, SPOHNC is sporting a new logo. We decided it was time for a fresh, new look, and we found the perfect group to help us. The Carleton Group, a student run advertising agency at New York Institute of Technology, was the brainchild behind the new logo design. Admittedly, they have helped us with quite a few other projects as well. The Carleton Group gives its students real world experience in graphic design, social media and branding. They are also led by some amazing professors who are professionals in the field. We think they're all pretty awesome!

We're not giving much away here, but rest assured you will be treated to quite a few other new projects and ideas in the coming months, especially as we head into April Awareness Month. Keep an eye on your inbox, our social media and SPOHNC's website too. We're excited about a lot of things we've been working on, so get ready for some great, new and very inspiring stuff!

In Memoriam

Harold "Buddy" Hood

SPOHNC was saddened to learn of the recent passing of Harold "Buddy" Hood. Buddy, along with his wife Sharon, was the Co-Facilitator of the Macon, Georgia SPOHNC Chapter support group since 2019.

As a head and neck cancer survivor, Buddy was able to offer a special brand of hope to those who came to the Macon group for inspiration, information and camaraderie. He was dedicated to the group and those he helped along their cancer journey. In addition to his love of helping people, Buddy also enjoyed hunting, reading, and especially his grandchildren.

We appreciate Buddy's dedication to the community of head and neck cancer patients and survivors that he served as part of our SPOHNC family, and we will miss him very much. Our thoughts and prayers remain with his family, and the attendees of the Macon, Georgia SPOHNC Chapter support group family.

*May God give you... for every storm, a rainbow,
for every tear, a smile, for every care, a promise,
and a blessing in each trial. For every problem life
sends, A faithful friend to share, For every sigh, a
sweet song, and an answer for each prayer.*

Irish Blessing



“Like” SPOHNC on Facebook

SPOHNC's March Champions of Hope

Bill & Linda Clyne - Greenville, SC SPOHNC Chapter Support Group Facilitators

If you haven't met Bill and Linda Clyne, you're really missing something in your life. This amazing couple came to SPOHNC in 2013, following Bill's diagnosis and treatment for unknown primary cancer of the head and neck in 2006. Little did any of us know (the Clyne's included) how their journey would bring them across the United States, from California, to the East Coast, where they settled in, and began the new journey of being the Facilitators of the Greenville, SC SPOHNC Chapter. The Chapter had been in existence but had experienced some bumps in the road. Bill and Linda used their special brand of tenacity to rebuild the group, and they haven't looked back since.

At SPOHNC's 20th Anniversary Conference and Celebration of Life, it was our joy to meet this awesome couple, who flew across the country to be a part of the weekend celebration, along with several hundred other patients, survivors and caregivers as well. After a brief (and hilarious) introduction, we instantly knew that this couple would become an integral part of our SPOHNC family...and we were spot on!

Bill and Linda are both also part of SPOHNC's National Survivor Volunteer Network, as survivor and caregiver volunteers. Always at the ready, they both have been matched with many, many patients and caregivers who have come to SPOHNC seeking sport and a listening ear. They have even been known to plan a road trip or two, to have lunch and meet up with their matches in person (even if it involved a 4 hour car trip, because, hey – why not?).



The Clyne's support group has always been a close knit one – the kind where they check in with each other socially outside of the meeting day and time. They really are like a family, and we have no doubt that in addition to support and a listening ear, they provide a laugh or two along the way. Good medicine, right? If you haven't ever read Linda's sharing story, take a look at our website at SPOHNC.org (<https://www.spohnc.org/bill-and-linda-clynes-story/>). Linda is quite the writer, so prepare yourself for a good, heart healthy belly laugh! Incidentally, their support group has also served as the face of SPOHNC's closed Facebook group for patients, survivors and caregivers and

their families, as well as gracing the front cover of the SPOHNC brochure for quite a while now.

As dedicated and creative Facilitators, Bill and Linda have hosted many special celebrations throughout their meeting years in Greenville as well. Especially meaningful is their February celebration where they honor caregivers. Gifts and acknowledgements abound at that meeting, and the celebration is one that is fondly spoken of and remembered by all. Of course, like so many other meetings and events, Covid has put a damper on these celebrations (and their in person meetings) for the last 2 years, but the Clyne's have slowly started up their in person meetings once again, and they will be back in action, supporting others in person, instead of on the phone, in no time at all. We're sure their attendees look forward to getting back together to share what's been happening in their lives these last 2 years.

During this fine month of March (which also happens to be Bill's birthday month), let's pay tribute to an amazing couple, Bill and Linda Clyne, and celebrate them as SPOHNC's March Champions of Hope. A well-deserved honor for two of our favorite members of our SPOHNC Family. Congratulations, our guys!

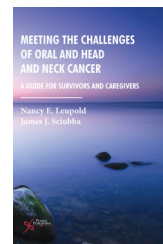


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April Awareness Calendar

We hope you're getting ready for April Awareness. As of press time, the events listed here are already scheduled with more to come in the weeks ahead. If you live in the area of an event or illumination, take some photos and send them to info@spohnc.org. We will publish them in a future issue of the newsletter, with full photo credit to you.

SPOHNC Wants to Hear From You!

SHARE YOUR NEWS
WITH US!

Share your exciting news, and important or memorable occasions with SPOHNC.

Connect with us at info@spohnc.org

Don't Miss Out!

Keep your SPOHNC membership current. Enjoy all 8 issues of "News from SPOHNC"

Also remember if you have moved, or changed your email address or phone number, be sure to contact SPOHNC at 1-800-377-0928 or email us at info@spohnc.org to let us know.

2022 APRIL ILLUMINATIONS

Date of Illumination	Location of Illumination
April 1 st	The Helmsley Building at 230 Park Avenue, NYC
April 3 – 9 th	Steel Stacks – Bethlehem, PA
April 4 th	Sperry Tower – Eagan, Minnesota
April 6 th through April 8 th	Indiana Power and Light
April 8 th	Zakim, Longfellow and Fore River Bridges – Boston, MA
April 12 th	The Wells Fargo Lights at 55 S. Tryon - Charlotte, North Carolina
April 14 th through April 16 th	Water Tower - Gilbert, Arizona
April 17 th	Columbia Center - Seattle, WA
April 22 nd	888 Boylston and the Boylston Plaza – Boston, MA

2022 ORAL CANCER SCREENING EVENTS

April 2	Lincoln, NE SPOHNC Chapter Support group
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Need materials for an event?

Call SPOHNC at 1-800-377-0928

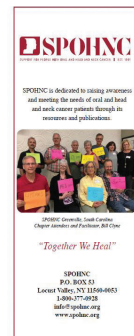
Order Your April Awareness Swag!

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Wristbands
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Awareness Pins - \$6.50 ea. (for up to 9)
\$6.00 ea. for 10 or more



CHAPTERS OF SPOHNC

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

PLEASE NOTE: Many Chapters are not holding meetings in person at this time due to COVID-19.

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

Please call to SPOHNC at 1-800-377-0928 to find out more information.

ALABAMA
BIRMINGHAM

ARIZONA
CHANDLER, GILBERT
PHOENIX (2), SCOTTSDALE

ARKANSAS
FAYETTEVILLE

CALIFORNIA
ARROYO GRANDE, LOS ANGELES
NEWPORT BEACH,
ORANGE-UCI, SANTA MARIA,
SOUTH SAN FRANCISCO,
STANFORD, VENTURA

COLORADO
DENVER

DC
GEORGETOWN

FLORIDA
DEERFIELD BEACH, FT MYERS,
JACKSONVILLE (2), NAPLES,
PALM COAST NORTHEAST,
WINTER PARK

GEORGIA
ATLANTA, MACON,
SAVANNAH

IDAHO
MOSCOW

ILLINOIS
EVANSTON, MAYWOOD,
MORRIS, SPRINGFIELD

INDIANA
AVON
SOUTH BEND

IOWA
DES MOINES

KANSAS
KANSAS CITY

LOUISIANA
BATON ROUGE, NEW ORLEANS

MARYLAND
BALTIMORE-GBMC, BALTIMORE-JHMI,
LIBERTYTOWN

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DANVERS

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ANN ARBOR, SAGINAW, WARREN

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MINNEAPOLIS, ST. PAUL

MISSOURI
ST. LOUIS/DPCC

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LINCOLN, OMAHA/MCC

NEW HAMPSHIRE
CONCORD

NEW JERSEY
CAMDEN,
LONG BRANCH, MORRISTOWN
PRINCETON/UMC

NEW YORK
BAY SHORE, BUFFALO,
MANHATTAN/BI, MANHATTAN, LH
MANHATTAN/MSDUS,
MANHATTAN/NYU, MIDDLETOWN,
NEW HYDE PARK,
ROCHESTER, SOUTHAMPTON,
STONY BROOK, SYOSSET,
WHITE PLAINS,

NORTH CAROLINA
DURHAM

OHIO
CINCINNATI,
DAYTON

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SOUTHERN OREGON

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CHARLOTTESVILLE, FAIRFAX,
NORFOLK

WASHINGTON
KIRKLAND

WEST VIRGINIA
MORGANTOWN

WISCONSIN
APPLETON

*"Thanks for everything you do.
When I was diagnosed. SPOHNC
was the only reliable source of info
for OHNC patients and families."*

~ Valerie T.



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