

SPOHNC

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



October Champion of Hope

A champion for many!
Turn to page 6.

Welcome David Goldenberg, MD, FACS

Read more on page 11.

In Memoriam - A Beloved SPOHNC Volunteer

SPOHNC pays tribute on page 15.

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Rick Agee P.K. Golf Event
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Sinonasal Malignancies and Cancer of the Nasopharynx

Nyall London, MD

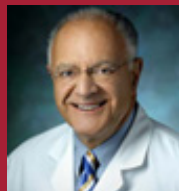
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SPOHNC is dedicated to raising awareness and meeting the needs of oral and head and neck cancer patients through its resources and publications.

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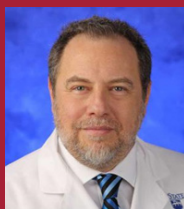
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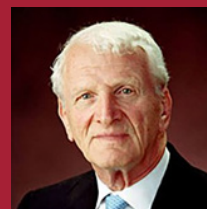
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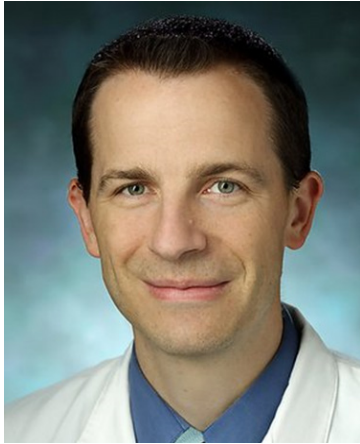
Chris Leonardis

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Sinonasal Malignancies and Cancer of the Nasopharynx

Sinonasal malignancies, tumors that arise inside the nose and nearby sinus area, are an uncommon subset of head and neck cancer. These are a diverse group of malignancies and include sinonasal squamous cell carcinoma (SNSCC), olfactory neuroblastoma, nasopharyngeal carcinoma (NPC) and others.



Initial symptoms are not specific for sinus cancer and can include difficulty breathing through the nose and nosebleeds, which are commonly seen due to benign sources like sinus infection and

septal deviation. Thus, sinonasal tumors may grow to be large before they are diagnosed.

A heightened awareness and concern for a sinus tumor should be raised when symptoms also include facial numbness, double vision, or protrusion of the eye. This is because these tumors grow close to the eye, important nerves of the face, and the brain. Sinonasal tumors may also be related to viruses such as the Epstein Barr Virus (EBV) for NPC or the human papillomavirus for SNSCC. Sinonasal tumors are rare, their treatment complex, and thus, should be treated by high-volume multi-disciplinary cancer treatment teams. In this article we will discuss common questions related to the diagnosis, treatment, and long-term care of patients with sinonasal malignancies.

Diagnosis: Getting the correct diagnosis can be challenging as many of these tumor types may look similar under the microscope. However, getting the correct diagnosis is essential because there are many different types of sinonasal tumors and the treatment varies significantly for each type.

How can I assist with obtaining the right diagnosis?

It is recommended that any biopsy sample be evaluated by an expert head and neck pathologist familiar with distinguishing sinonasal tumors. If one is not available at your institution, a second opinion pathology review by an outside head and neck pathology specialist is recommended.

What additional studies are important for diagnosis and treatment?

A computed tomography (CT) scan is ideal for evaluating bone invasion and a high-resolution magnetic resonance imaging (MRI) study is ideal for evaluating soft tissue infiltration. Together these imaging studies help to ascertain whether a tumor has broken through bone protecting the eye and brain and whether the tumor may be growing into these structures or along nerves. Although it is uncommon for sinonasal malignancies to spread to other locations in the body, it is important to perform additional imaging such as either a PET-CT scan or a CT scan of the neck, chest, abdomen, and pelvis to rule out distant tumor spread.

When is a biopsy performed?

Obtaining a biopsy sample is important to establish the proper diagnosis. A biopsy may be performed either during a clinic visit or in the operating room depending on a variety of circumstances. Prior to performing a biopsy, it is important to have performed imaging of the mass. This can help avoid biopsy of lesions that should not undergo a biopsy such as an encephalocele (portion of brain protruding into the nose) or a tumor that may be rich in blood vessels. Additionally, if body imaging identifies a potentially area of concern for spread in the neck or elsewhere in the body a needle biopsy by an interventional radiologist may be recommended. Either an ultrasound or CT scan may be used to guide placement of the biopsy needle into the appropriate location.

Treatment: After clinical evaluation by a multi-disciplinary cancer treatment team including an otolaryngologist – head and neck surgeon, radiation oncologist, and medical oncologist, sinonasal malignancy cases should be presented at a group at your institution called a multi-disciplinary tumor board for discussion. The tumor board is a collection of specialists at an institution including head and neck cancer surgery, radiation and medical oncology, radiology, pathology, and other specialists. Case presentation may include review of pertinent imaging studies, pathology, and other exam findings followed by a

multi-disciplinary discussion and treatment recommendations.

How will my tumor be treated?

The answer to this question is complex and depends on a large number of factors including the tumor type and disease extent. Some tumor types such as primary NPC respond well to non-surgical approaches such as radiation and chemotherapy and therefore are seldom treated with surgery except if they recur. Other tumor types may respond more favorably to primary surgical approaches; however, the decision whether to perform surgery depends on the disease extent and whether the tumor can be completely removed by surgery. Some cancer centers advocate for induction chemotherapy approaches for tumors including sinonasal undifferentiated carcinoma (SNUC) and other locally advanced tumors. In this scenario several rounds of chemotherapy may be given prior to establishing whether definitive treatment will be non-surgical or by surgical methods.

Should my surgery be performed endoscopically?

Surgically removing sinonasal tumors through an endoscopic approach, with cameras and instruments through the nostrils without making incisions on the head or face, has gained increasing popularity in past years. However, whether your tumor should be removed endoscopically or through an open craniofacial approach depends on a variety of circumstances.

In most cases, the goal of surgery is to remove the entire tumor and obtain negative pathological margins. This goal should not be compromised when a surgical approach is chosen. Some sinonasal tumors may not be amenable to an endoscopic approach such as those that involve the skin, eye, and palate. In some cases an endoscope may be used to assist tumor removal during an open approach.

What are the side effects of treatment?

The side effects of treatment vary greatly depending upon the extent and type of surgery, as well as the type and amount of radiation therapy or chemotherapy utilized in the treatment plan. Common side effects of surgery

may include pain, nosebleeds, nasal congestion, numbness, nasal crusting, loss or change in sense of smell and others. The severity of nasal crusting can be more pronounced when surgery is combined with radiation therapy and may take longer to resolve. Additional side effects of radiation and chemotherapy may include dry mouth, change in taste, numbness in the fingers or toes, fatigue, decreased immune cell function, nausea, loss of appetite, and others.

Long-term: Completion of treatment is only the beginning and there are significant long-term impact and considerations for patients with sinonasal tumors.

What is cancer survivorship?

Cancer survivorship has many definitions but starts at cancer diagnosis and entails a long-term care management plan to optimize patient well-being. This plan may involve a cancer survivorship nurse or internal medicine physician. Patients may find it useful to join support groups to allow for interaction with other patients who are undergoing similar experiences. a patient may ask about local cancer support groups. There may be national groups available such as SPOHNC. Certain types of sinonasal tumors are so rare they only affect a couple hundred patients in the United States per year thus it may be challenging to find a specialized support group. One example is olfactory neuroblastoma (ONB) for which specific support groups may be found on social media and ONB-specific patient centered events are conducted on an annual basis (<https://www.cancer.gov/pediatric-adult-rare-tumor/rare-tumors/other-rare-tumors/olfactory-neuroblastoma>).

What is included in and what is the duration of cancer surveillance?

After completion of treatment, it is important for the patient to follow closely with the cancer treatment team for cancer surveillance. This includes regular clinical visits and physical exam and nasal endoscopy for close evaluation of the sinonasal cavity. This may also include high-resolution MRI imaging of the sinonasal cavity as well as surveillance imaging of the neck and chest according to standard head and neck cancer practices. The duration of surveillance varies for sinonasal malignancies. Some sinonasal tumors such as ONB can recur 20 years later, thus cancer surveillance may be life-long for some sinonasal tumor types. For virally associated tumors such as EBV+ NPC, surveillance may also include blood tests to assess for the presence of EBV in the blood as a potential marker of the tumor coming back.

What if my cancer comes back?

Close surveillance with your cancer treatment team is important to try and help detect cancer recurrence early. Should a cancer

recurrence unfortunately occur, a similar process with a multi-disciplinary cancer team evaluation, biopsy, and thorough imaging studies are important to assess the extent of disease. Presentation of your case at a multi-disciplinary tumor board is important to determine which manner of treatment may be best for your particular case. Clinical trial opportunities may be available or search for clinical trial opportunities that may be available at other institutions (www.clinicaltrials.gov).

Disclaimer: This article contains generalized advice and is not a substitute for personalized medical care and recommendations. It is important to work closely with a multi-disciplinary cancer treatment team during diagnosis, treatment, and continued long-term surveillance.

Editor's Note: Dr. London was born and raised in Southern California. He received his bachelor's degree in Microbiology from Brigham Young University followed by his M.D. Ph.D. from The University of Utah. Dr. London then completed his residency in Otolaryngology-Head and Neck Surgery at Johns Hopkins. He then completed a fellowship at The Ohio State University in open and endoscopic skull base surgery under the direction of Dr. Ricardo Carrau.

“Thank you for all of this;
it's such a relief to know
that an organization like yours exists.”

~ Leanne

SPOHNC Chapter News

Syosset, NY Welcomes Special Guests

SPOHNC Chapter support groups can sometimes benefit from special speakers attending their meetings, and the September Syosset, NY SPOHNC Chapter support group meeting was no exception. The in person meeting was held on September 14th at the Town of Oyster Bay Ice Skating Center.

At the meeting, Rayna McCann, MS, RDN, CSO, CDN, LI Territory Manager for Kate Farms, led a discussion about their products and how they can help with the special nutritional needs of oral, head and neck cancer patients and survivors. Rayna is an established Registered Dietitian (RD) and a Board Certified Specialist in Oncology Nutrition (CSO). She is a Registered Yoga Teacher (RYT-200) and yoga4cancer certified. Rayna is a proud Territory Manager for Kate Farms, representing the Long Island and Queens area, where she works to bring quality nutrition to patients throughout the continuum of care.

Kate Farms products, which include shakes and formulas, are unique because they are Certified USDA Organic, Non-GMO Project Verified and made without common allergens. They are plant-based products scientifically designed to provide you with everything you need and nothing you don't.



Many head and neck cancer patients and survivors experience swallowing problems so the presentation was relevant, and very much appreciated by those in attendance. Rayna and her colleague Eric were kind enough to bring samples of Kate Farms various products to the meeting, for anyone interested in trying them out. There was time at the end for questions, and an opportunity to sample some products

and also pack them up to take home as well.

Thank you Rayna and Eric, for your lively and informative presentation, and thank you Frank, for connecting the dots to make this presentation happen. Great things are happening at our SPOHNC Chapter Support group meetings!

October Champion of Hope

Polly Ubben, Lincoln, NE SPOHNC Chapter Facilitator

SPOHNC's October Champion of Hope is one of our busiest SPOHNC Chapter Facilitators. Polly Ubben, MA, CCC-SLP-L has been the Facilitator of the SPOHNC Lincoln, Nebraska Chapter for more than 7 years. She has been a cheerleader, friend, confidante and supporter to many in her SPOHNC Chapter support group, keeping them informed along the way, through presentations at support group meetings, and through sharing information like our SPOHNC publication, *We Have Walked In Your Shoes*, and our *News from SPOHNC* newsletter. Every newly diagnosed patient that comes to Polly, feels hope right away, through her caring guidance and professionalism, and every survivor and caregiver feels the same.



In 2021, Polly and her SPOHNC Chapter support group put together their first ever free community oral cancer screening clinic. This was a huge undertaking for a group that had never done anything like this before. Some of the participants in addition to group attendees, included a school of dentistry, ENT's, cancer nurse navigators, Aging Partners in Lincoln and the Heartland Cancer Foundation as well. The turnout was terrific for a first ever event, and the group felt good about raising awareness of oral, head and neck cancer awareness in their community. Both Polly and her Co-Facilitator, Regina, led the charge with a "super group" that helped coordinate and facilitate the event. For the first event of its kind in Lincoln, Nebraska, made a huge impact!

She also recently hosted a "Husker" tailgate before a home football game. There were games, prizes and two guest speakers...Her new son-in-law and daughter, both of whom are in the medical profession, and helping cancer patients and survivors. Polly is amazing! A true blessing. Our angel!

Over the years, SPOHNC has received many accolades about Polly, from those she has supported, through her group. Here are just a few!

"She is truly an amazing person, that shows by how much she cares for each of us. Not just as a client/patient, but as an individual. She is constantly bringing in speakers to educate, encourage and provide information for pre, current and post treatment patients. I've always considered her as one of my "angels" that got me through oral cancer." ~ *Scott W.*

"I'm sure many of those who have had their lives touched by Polly would agree she is a true angel. It is hard to define her mission and my suggestion would be: come see her, listen to her, watch her with patients, and the short time with our group and I am sure you will understand how caring for others defines her being." ~ Ken F.

Some others in her group have defined Polly as "a great therapist, leader of our SPOHNC group and a good friend." She is always there for us whenever we need help or answers about something." ~ James H.

"She is one of my heroes. Her commitment to her patients is not a job it's a calling. She's all in, and we're all in with her." ~ Brad B.

"Life would be much more difficult without her help." ~ Angie

Group attendees tell SPOHNC that they have learned from the guest speakers at their monthly meetings. Polly does her best to stay informed about all the things that are new in her field and tries to help everyone that she can.

Polly is dedicated, selfless and goes above and beyond consistently, to support those who cross her path each day. She puts her patients and survivors first, and makes sure they have what they need, and more, along their cancer journey.

And so, it is our pleasure to honor Polly Ubben, as SPOHNC's October Champion of Hope. We congratulate you!

We are grateful, we are blessed to count you among our dearest members of our SPOHNC family, and, to borrow some words from Les L, who attends your group... "I know we don't say this often enough - Thank you Polly for all that you do!"

Together, WE Heal



Sharing Love
and Hope,
One
Donation
at a Time.



Dear SPOHNC Family & Friends,

Thank you for supporting SPOHNC for more than 32 years. Your support has made an immense impact. Your commitment and generosity have given the organization the ability to provide a place where patients, survivors, and caregivers feel safe, encouraged and hopeful.

According to the American Cancer Society, **1 in 4 cancer patients suffer from depression** in America. SPOHNC remains committed to meeting the needs of those diagnosed with head and neck cancer, through our programs and services, that increase vitality and create positive health outcomes, day after day. None of that would be possible without the support of donors like you!

First, let us ask you:

- * Did you or a loved one call SPOHNC when it seemed like there was nowhere to turn? Our **highly devoted staff receives calls daily, helping individuals find access to social, medical, or financial assistance** and many other types of support.
- * Did we connect you with a SPOHNC volunteer who provided attention, care and kindness? This year alone, SPOHNC has matched more than 300 patients and caregivers with survivor and caregiver volunteers. We have **matched more than 10,000 in our 32-year history**.
- * Did we connect you with one of our **100 chapters**? SPOHNC's support groups are attended by many head and neck cancer patients, survivors and caregivers. Our volunteer Facilitators make it their mission to **educate, encourage and share the message of hope**.
- * Did we help you find **lodging, transportation, nutritional information, a treatment center, a healthcare or dental clinician**? Or did we **help you manage the emotional and mental distress** you were experiencing?
- * Did you find SPOHNC's newsletter filled with **expert health insights and inspiring stories** helpful, regardless of which phase of the disease you are in?
- * Did you find support, camaraderie and understanding through SPOHNC's social media platforms, including Instagram and our private Facebook page just for patients, survivors, and caregivers?
- * Did you learn about emerging treatment options through SPOHNC's partnerships and information on clinical trials? **More than 200 individuals have inquired** about clinical trials through the navigation tools offered on our website.

Your support can have an invaluable impact on navigating a head and neck cancer journey. Your commitment empowers us to provide hope, a brighter future, and essential support to more people like you, now and in the future. Together, we ease the path for families, patients and the head and neck cancer community.

Please look into your heart and give a gift today. Together WE, Heal!

With much gratitude,
Mary Ann Caputo
Executive Director



Congratulations Are Due!

Our SPOHNC staff family has grown, so we wanted to share the happy news with all of our readers!

SPOHNC's Executive Director, Mary Ann Caputo, and her family, recently welcomed a new baby boy. Connor William Caputo was born on August 17th, in beautiful San Diego, California. Proud parents of Connor are Larry Caputo and Megan Caputo. Mary Ann and her husband, Larry, recently took a trip to California to meet Connor, and spent some family time together with everyone. Connor is Mary Ann's 4th grandson, joining his big brother, Michael, and his cousins Frankie and Ayden. Congratulations to all!!



In more exciting news... SPOHNC's Social Media maven, Christina, welcomed a beautiful baby girl, Nova Demi, on September 16th. Nova is lucky to have big sister, Ly'Anna, to watch over her. Ly'Anna is thrilled about her new little sister and she can't wait to babysit! Congratulations to Christina and Josh and family!

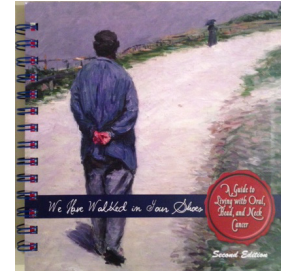


SPOHNC's RESOURCES

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

Peanut Butter Chocolate Shake

Ingredients

- 1 1/2 cup heavy whipping cream
- 3 tbsp chocolate syrup
- 2 tbsp creamy peanut butter
- 2oz chocolate ice cream

Directions:

- 1 Pour all ingredients in a blender.
- 2 Process until well blended.
- 3 Chill.

1392 Calories

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

Eat Well Stay Nourished

A Recipe and Resource Guide for Coping With Eating Challenges

compiled by

Nancy E. Leupold, Founder

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Having head and neck cancer can be a battle.
Patients can help to move the research AHEAD.



Head and neck cancer includes cancers of the mouth, nose, sinuses, salivary glands, throat, and lymph nodes in the neck. Adults with head and neck cancer may consider asking their doctor about the AHEAD-MERIT study of an investigational vaccine for HPV+ head and neck squamous cell carcinoma that has returned or spread.

Go to
ahead-merit.com
to learn more



Survivor Serenade - Sara Pray

Survivor and vocalist Sara Pray, of Lewisville, Texas, recently performed at a local taco restaurant, and survivor, Jack and caregiver, Maryellen Mitchell attended, and sent along a video to SPOHNC's Executive Director, Mary Ann Caputo. Great job Sara! The lucky audience was treated to Sara's rendition of Peter Gabriel's hit "In Your Eyes."

Sara has been part of the SPOHNC family for many years, even performing at past events like the Rick Agee Skate/Run for Fun, and other events as well. She's a popular voice in the Texas head and neck cancer community. Thank you for serenading the crowd as they enjoyed their tacos, Sara!



Calling All Massachusetts Head and Neck Cancer Survivors!



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

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

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

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

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

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

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

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

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

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

SPOHNC deeply apologizes
for the omission of

The Simms Foundation
as a
Benefactor

in the Spring 2023
issue of
"News from SPOHNC"

News from the Board Room

SPOHNC's Board of Directors is honored to welcome its newest member, David Goldenberg, MD, FACS. Dr. Goldenberg joins a highly respected group of professionals in the field of head and neck cancer, and we are grateful for his willingness to become such an integral part



of our SPOHNC family. David Goldenberg, MD, FACS, is a Head and Neck Surgical Oncologist. He was educated at the Ben Gurion University in Israel, and completed a residency in Otolaryngology-Head and Neck Surgery at

Rambam Medical Center in Haifa, Israel. He also did a three-year fellowship in Head and

Neck Surgery and Oncology at the Johns Hopkins Hospital in Baltimore. He then went to Penn State Hershey where he has remained for the past 18 years as the current Professor and Chair of the Department of Otolaryngology-Head and Neck Surgery at the Penn State Health Hershey Medical Center as well as Vice President, Otolaryngology – Head and Neck Surgery Services. Dr. Goldenberg is an internationally recognized expert on head and neck cancers, including thyroid cancer, thyroid, and parathyroid surgery. In addition, he teaches medical students, residents, and fellows and is a Penn State College of Medicine Distinguished Educator. He is a funded researcher, and his clinical research focuses on outcomes and etiology of the rise in the incidence of thyroid cancer. In addition, his basic research lab and translational research focus on head and neck and thyroid cancer genomics.

Dr. Goldenberg is an accomplished and prolific author of 250 journal articles, 40 book chapters, and seven books in the field of head and neck and thyroid oncology and surgery.

We welcome you, Dr. Goldenberg and we look very much forward to working with you.

Survivor & Caregiver Happenings Up, Up and Away!!!!

Survivor and Caregiver, and SPOHNC Greenville, South Carolina Facilitators, Bill and Linda Clyne recently saw an event on their Friday news and decided to “seize the day!” They have been known for adventures like zip lining, and jumping off a ship into freezing cold Alaskan waters, but this one is truly unique!

Hot Air Affair: Rising Above Cancer held for its 6th year, on Labor Day weekend, brings balloons from across the United States to beautiful Anderson County, South Carolina. The proceeds of this wonderful event benefit the Anderson County Cancer Society, which helps cancer patients in the county by providing financial, emotional and physical assistance to local cancer patients.

Here's what Linda told us about their adventure...“We saw it on the news Friday night and said “yes! Let's do it!” We didn't have

much info except the fly times and when we got there found out most of the flights were booked ahead of time online. The advertised \$25 “ride” was a quick up and down on a tethered balloon.



I think we happened upon the only two available spaces for a “free flight” and it was substantially more than \$25...but OH! what a lovely, peaceful ride. I could look forward and down at a diagonal - not straight down, but it was a blast! We were in the air for over an hour and landed in the front yard of a house where the woman sitting on her porch had quite a show!

As we were coming in for landing there was a pasture across the street from this yard with longhorn cattle that we spooked. They started running and almost broke out of the fence! Linda also shared with us “On my bulletin board is a quote from some unnamed source that says, “When was the last time you did something for the first time?” Last night definitely qualified as a “first!””

SPOHNC can say that it's also the first time we have ever shared this as a Survivor and Caregiver News piece in our newsletter. How exciting!!!!

How Can I Help?

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



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

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

Share Your Story

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

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



Medical Advisory Board News

2023 WIO Helen F. Krause, MD Trailblazer Award Recipient

This year's awardee of the AAO-HNS Women in Otolaryngology (WIO) Helen F. Krause, MD Trailblazer Award is **Amy Y. Chen, MD, MPH, MBA**. This award recognizes an individual who has furthered the interests of women in the field of otolaryngology.

Dr Chen is the Willard and Lillian Hackerman Professor and inaugural vice chair for diversity, equity and inclusion (DEI) of the Department of Otolaryngology and Head and Neck Surgery at Emory University School of Medicine. She also co-leads the DEI efforts at Emory's Winship Cancer Institute. She serves as Emory's director of head and neck endocrine surgery and is the program director for the endocrine head and neck surgery fellowship. Dr. Chen is also the newest member of SPOHNC's Medical Advisory Board.

Dr. Chen has been a trailblazer in promoting the interests of women in her specialty. She was the first female faculty member to join the



Department of Otolaryngology Head and Neck Surgery at Emory in 2001. In 2010 she became the first woman and person of color to attain the rank of full professor in otolaryngology at Emory. She has served as a mentor and sponsor for women faculty and faculty of color in countless ways, implementing the first Women in Surgical Specialties group at Emory in 2019 and advocating for faculty and staff with children as cochair of the Child Care Task Force for the Emory University Senate.

On a national level, she founded the Women in Head and Neck Surgery service in the American Head and Neck Society. There she established the first mentoring program offered by any national otolaryngology society and was a founding member of its DEI Committee.

Her academic research has focused on disparities in healthcare, particularly the effect of socioeconomic status and insurance coverage on outcomes in head and neck cancer, which resulted in appearances before Congress. Dr. Chen also led inaugural efforts to raise awareness of unconscious bias throughout Emory University School of Medicine. She serves on the Board of two social justice non-profit organizations: Partnership for Southern Equity and the Asian Pacific Institute on Gender-Based Violence.

On the Links With The Rick Agee Foundation

For the 8th year in a row, friends and family took to the greens on Saturday, June 23, 2023 and Sunday, June 24, 2023 to honor the memory of their dear friend, brother, son, uncle, colleague, Rick Agee. Rick was a devoted husband, father and a committed, selfless SPOHNC



Jack and Maryellen Mitchell, SPOHNC's Dallas area Support "team" Facilitators and dear friends of Rick, and SPOHNC, were honored with the gift of a poster presentation of the "News from SPOHNC" article naming them as SPOHNC's Spring 2023 Champions of Hope. This honor was much deserved by one of our favorite couples!!

volunteer. He started this golf event years ago as a way to reconnect with some old friends, and the tradition continues as a way to honor his memory. The event takes place every year at The Cliffs Resort on beautiful Possum Kingdom Lake in Graford, TX.



On behalf of SPOHNC, we extend a HUGE thank you to Kerry and Janie Agee, for hosting the 2023 Rick Agee P.K. Golf Event, and for helping to continue Rick's legacy. Many thanks to your family and friends for continuing to support the many programs, resources, and publications SPOHNC offers to the head and neck cancer community. SPOHNC is forever grateful to you for making a difference in the lives of those who are diagnosed with oral, head and neck cancer. We know Rick continues to look down on your event every year and

Nearly 100 golfers took to the links in the Texas heat, and despite it all, they had a wonderful 2 days of friendship, trading stories and sharing in the camaraderie of the event. There was food and drink, there were lots of great raffle prizes and even a few surprises along the way.

feel the love! We appreciate all the work and time that you put into this event. Our hearts of full of gratitude.

This years' winners for Par 3 - "Closest to the Pin" were Hole 3 Hayden James, Hole 6 Randy Morgan, Hole 9 John Agee, Hole 12 Adrian Muehlstein, Hole 15 Blake Dyer.

SPOHNC will always remember Rick for his amazing spirit for making a difference in the lives of many, and for the kind and caring smile he always wore. He will remain a part of the SPOHNC family and will be forever in our hearts.

Jack Mitchell said it best..."Good times, Good Friends, and Good Cause! Thank you!"



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SPOHNC's Patient Advocacy

SPOHNC attended the 2023 American Society of Clinical Oncology Annual Meeting in Chicago, from June 2 through 6th, 2023. This wonderful opportunity was the result of being chosen for the Patient Advocacy Pavilion at ASCO, which gives SPOHNC the chance to connect with more than 40,000 attendees who are healthcare clinicians and researchers from all over the world, and other patient advocacy organizations as well.

One of the most exciting parts of the weekend was the Patient Advocacy Reception on Friday night, hosted by Merck Pharmaceuticals. The keynote speaker for the event was Gary A. Puckrein, PhD – President and CEO of The National Minority Quality Forum.



The National Minority Quality Forum was founded in 1998 to address the critical need for strengthening national and local efforts to use evidence-based, data-driven initiatives to guide programs to eliminate the disproportionate burden of premature death and preventable illness for racial and ethnic minorities and other special populations.

Dr. Puckrein is passionate about the NMQF and all of their initiatives, and his commitment to their programs was very apparent to all in attendance. He gave an inspiring keynote presentation and followed up with a panel of experts from his Board and the organization as well. There was a lively Q and A session, as well as the opportunity to network with other organizations and those in attendance from the NMQF. SPOHNC was one of more than 35 patient advocacy organizations that were privileged to attend this event and reception.

We enjoyed meeting Dr. Puckrein, and we look forward to supporting the NMQF in all of their endeavors.

Staying Connected through Communication Survey

The University of Washington SPEAC Lab is inviting individuals with head and neck cancer (with or without laryngectomy) to answer survey questions about their communication experiences. We ask participants to have at least one family member, friend, or coworker to also answer survey questions. Your participation will help healthcare providers support people with head and neck cancer and the important people in their lives to stay connected through communication. This is an online survey study that will take about 30-45 minutes. We can also mail out a paper survey. People with head and neck cancer and their family / friends / coworkers will complete SEPARATE surveys. This study is open to anyone in the U.S.

Each person will be paid \$25 for completing surveys.

To access the survey link, visit: <https://sites.uw.edu/speaclab/>

The person with head and neck cancer/laryngectomy needs to start first and then nominate their family member / friend / coworker to participate.

If you would like to check if you have already done this survey, or have any questions, please email us at speaclab@uw.edu or leave us a voicemail at (206) 221-3563.

A promotional graphic for a survey. It features a dark red background with white text. On the right side, there is a photograph of several hands raised in a meeting or discussion. The text reads: "Paid online survey about communication experiences". Below this, it says "We want to hear from:" followed by a bulleted list: "• People with head and neck cancer", "• With or without laryngectomy; and", "• Their family members, friends, and coworkers". At the bottom, it states "This online survey is open to eligible participants living in the U.S.".

Paid online survey about communication experiences

We want to hear from:

- People with **head and neck cancer**
- **With or without laryngectomy; and**
- Their family members, friends, and coworkers

This online survey is open to eligible participants living in the U.S.



To begin, scan the QR code or visit: <http://sites.uw.edu/speaclab>

In Memoriam - Ronnie Trentham

Our SPOHNC family was deeply saddened to learn of the passing of one of our most beloved volunteers. Our dear friend, Ronnie Trentham, passed away on May 15th, 2023. SPOHNC feels this tremendous loss from our community, deep within our hearts.

Ronnie was one of the most inspiring volunteers we have ever had the pleasure of welcoming into our SPOHNC family. He joined us in 2008 when he found SPOHNC, and his wife Lorie convinced him to go to a SPOHNC Chapter support group meeting. It was there that he found people who understood what he was going through, and it was through the support group, that Ronnie decided to support others by joining SPOHNC as a volunteer for our National Survivor Volunteer Network matching program in 2008 as well. As they say, the rest is history. Since that time, Ronnie supported nearly 50 people through the matching program, treating each one with care and kindness, and making them feel welcomed, and important. Most importantly, he did this while going through his own trials and tribulations, and never said no to anything we asked of him. Ronnie was truly selfless, committed and full of gratitude and grace.

Ronnie's involvement with SPOHNC was not limited to the matching program. He was a regular attendee at Jack Igleburger & Lissa Applewhite's Fayetteville, Arkansas SPOHNC Chapter support group meeting, where he continued to lift up those who attended by always "showing up" for the group. If Ronnie was not involved in a family or community commitment, he was with his support group, providing help, and hope.

Ronnie spent 20 years as volunteer fireman, 4 years as a city councilman as well as 4 years as the Mayor of Stilwell, OK. He was also the 4H & FFA Booster Club President for 6

years, a CASA volunteer, and spent lots of time helping kids at school events and on trips as well. Ronnie was a giver, and a man of great faith. His church family was as much family as his biological family, which was clearly evident by the number of people who were in attendance as they honored his memory recently at New Life Church in Stilwell, Oklahoma. He volunteered at church as a greeter on Sunday mornings and served as a board member as well. He was also part of a Wednesday night group of men who were all seeking to strengthen their relationships with God and each other. The group was very special to him.



Ronnie spent 18 years as a member of the Stilwell Kiwanis Club, serving on various committees and as Kiwanis President in 2017 and 2018. He was a Hero of Hope for the American Cancer Society in 2010 and a Global Hero of Hope in 2015. His passion for helping people continued to grow as he began traveling with the Cherokee Nation's Tobacco Tour program, speaking to over 20,000 students about the dangers of using tobacco. His philosophy was always that if he could help just one person live a better, healthier life, then his own struggles would not have been in vain.

Ronnie was born in New Orleans and encountered several challenges along the way in his younger years. He never let those challenges define him. He said that all he ever wanted was a family, and he made the decision that he would be the best father and husband he could be if he ever had the chance to have a family of his own.

In 1978, Ronnie moved to Stilwell, Oklahoma with his Dad and brothers, and Stilwell became his home. He fell in love with the community and its people and began looking for ways to give back to the place that had made him feel so welcome. Over the next 45 years, Ronnie found many ways to serve his community.

He married the love of his life, Lorie, on March 29th, 1985. When Ronnie was diagnosed with cancer in 2003, they clung together through the hard days and celebrated each other on the good days. They had two daughters, Kyla and Kelsey and Ronnie flourished in the role of "Dad." Over the years, Ronnie became a bonus Dad to the many kids that would spend time in their home. He never failed to make every child feel welcome and important. That was his gift to the world...making everyone feel valued and loved, and SPOHNC knew that through the many phone calls that we had with Ronnie, where he would talk about his life, and the lives of those we had matched him with. There

was one particular patient caller who Ronnie had a tremendous impact on, sharing with us in a phone conversation... "I think I saved a life today."

Of all the titles Ronnie held in his lifetime, the title of "Papa" was his favorite. Becoming a grandparent was the highlight of his life. His grandchildren adored him and will forever carry his love in their hearts.

Ronnie loved hunting. Nights spent at the cabin swapping stories or road trips to Kansas provided time with men whose friendship was so important to him and was truly why he loved it so much.

Ronnie was truly one of a kind, and his love for God, his family, and his community showed throughout his life. Ever positive, no matter what he was dealing with, Ronnie's attitude shined through and he inspired everyone around him. He was a beacon for so many during their dark times, as he reminded everyone "do not give up!"

SPOHNC will miss Ronnie's sense of humor, the stories he would tell when he called us, and we will miss his innate ability to inspire and support those who came to SPOHNC seeking hope. He always had a way of doing just that. We will keep Ronnie's family and friends in our prayers and in our hearts, forever. He was a great man, and he will be missed by everyone whose life he touched, in his very special way.

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Head and Neck Cancer News

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

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

If you have any questions about the study, please email - ihaveavoice@dscience.com.

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Head and Neck Cancer News

Weekly Fosaprepitant Better Quality of Life During Chemoradiotherapy

Aug 2, 2023 - Alex Biese

Patients with nasopharyngeal carcinoma treated with concurrent chemoradiotherapy reported higher quality of life and were less likely to experience vomiting when receiving fosaprepitant every week as opposed to every three weeks.

Weekly fosaprepitant decreased vomiting in patients undergoing chemoradiotherapy, according to a recent study.

Patients with nasopharyngeal carcinoma (NPC) treated with concurrent chemoradiotherapy who received fosaprepitant every week were less likely to experience vomiting and had greater quality of life than those who received fosaprepitant every three weeks, according to the findings of a new study.

However, researchers also found that participants experienced no significant difference in their cumulative risk of vomiting or the need of rescue therapy (medication to relieve nausea and vomiting) whether they were treated with fosaprepitant weekly or every three weeks, according to the study published on July 27 in the journal JAMA Network Open.

The randomized clinical trial of 100 patients, with a mean age of 46.6 years and of whom 83% were male, ran from November 2020 to November 2022 at Sun Yat-sen University Cancer Center in China and was sponsored by Sun Yat-sen University, according to the trial's listing on clinicaltrials.gov.

It has been 15 years since the 2008 approval by the Food and Drug Administration (FDA) of injectable Emend (fosaprepitant dimeglumine) as part of a three-day combination treatment regimen to prevent acute and delayed chemotherapy-induced nausea and vomiting (CINV) for patients who received highly emetogenic chemotherapy (HEC). In 2016 single-dose injectable Emend, when combined with other drugs treating nausea and

vomiting, was approved by the FDA to prevent delayed CINV in patients who'd received moderately emetogenic chemotherapy (MEC).

“Unlike substantial evidence in the prevention of chemotherapy-induced nausea and vomiting (CINV), research in the prevention of nausea and vomiting caused by concurrent chemoradiotherapy (CCRT) is currently lacking,” Sun Yat-Sen University researchers wrote in the JAMA Network Open study, which they posited was to their knowledge, “the first study to assess the efficacy and safety of fosaprepitant during combined radiotherapy-HEC.” Participants were patients with previously untreated, histologically confirmed stage 2 to 4 nonkeratinizing NPC who had achieved CINV control, defined in the study as no vomiting or need of rescue therapy in the first 120 hours following the initiation of chemotherapy using a fosaprepitant-based regimen after two to three cycles of induction chemotherapy and were scheduled to receive intensity-modulated radiation therapy (IMRT) and concomitant treatment with the chemotherapy cisplatin every three weeks.

As a type of head and neck cancer, NPC starts in the nasopharynx, described on the American Cancer Society's website as “the upper part of the throat behind the nose and near the base of skull.”

There is less than one case of NPC per 100,000 people each year throughout most of the world, including in the United States, according to the American Cancer Society, which noted that NPC is more common in parts of South Asia, the Middle East, Africa and among native people in the Arctic, with up to 25 to 30 cases per 100,000 men and 15 to 20 cases per 100,000 women in areas of China.

The study's primary endpoint of complete response (no vomiting or rescue therapy during CCRT) was reached by 20.4% of patients receiving weekly fosaprepitant and 12.5% of patients who received fosaprepitant every three weeks. In the first 21 days of the study, 52% of patients who received weekly fosaprepitant did not experience vomiting, as opposed to 28% of patients who received fosaprepitant every three weeks. During the overall, 56-day period, 38% of patients on weekly fosaprepitant did not vomit, compared to 14% of patients on triweekly fosaprepitant.

(continued on p. 18)

Ninety-eight percent of patients who received weekly fosaprepitant experienced either no nausea or mild nausea with little to no interference with daily activities, versus 78% of patients receiving triweekly fosaprepitant, during the first 21 days, with 92% and 72% of patients, respectively, experiencing no clinically significant nausea during the 56 total days. Regarding quality of life, participants receiving fosaprepitant on a weekly basis “experienced less fatigue, nausea and vomiting, dyspnea (labored breathing), insomnia, and appetite loss and presented with better role function and emotional function compared with those who received fosaprepitant every three weeks,” the authors wrote. “As for the symptoms and functions of the head and neck, patients receiving weekly fosaprepitant were found to have significantly less problems regarding pain, swallowing, sense, teeth, xerostomia (dry mouth), sticky saliva, coughing, feeling ill and nutritional supplements.”

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The advertisement features a background image of a person drinking from a clear plastic cup. The text is overlaid on this image. The logo for MEIRAGTx is located in the bottom left corner of the advertisement.



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