

SPOHNC

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



SPOHNC's Advocacy Efforts

Read all about it on page 7.

April Awareness

Find out more on page 10.

Spring Champions of Hope

Everything is bigger in Texas!
Turn to page 13.

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“Together, WE Heal”

April Awareness month was a big success this year. Look inside to find out more about what was happening all across the United States!



Dental Implants & Treatment for Oral, Head and Neck Cancer Survivors- Part Two

Ryan S. Lee, DDS, MPH, MHA, FICOI, FAGD

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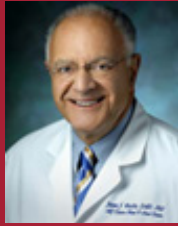
SPOHNC is dedicated to raising awareness and meeting the needs of oral and head and neck cancer patients through its resources and publications.

“TOGETHER, WE HEAL”

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In Memoriam*

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Dental Implants & Treatment for Oral, Head and Neck Cancer Survivors - Part Two

Ryan S. Lee, DDS, MPH, MHA, FICOI, FAGD

Am I a candidate for dental implants, even though I'm a cancer survivor?"

This is a follow-up commentary directed to the SPOHNC community concerning the viability of dental implant therapy and treatment for patients who completed head and neck radiation, chemotherapy, surgical resection and/or tissue



transplantation or transfer. Because the question "Am I a candidate for dental implants, even though I'm a cancer survivor?" is such a common one voiced

by our patients and their family members, these thoughts are relevant and practical.

Over time and with emerging experience of the dental community, many patients with treated oral and treated head and neck cancer have been successfully treated by capable dental practitioners including oral surgeons, dental oncologists and prosthodontists in the community who offer appropriate surgical and dental restorative services including placement of dental implants in such circumstances.

This follow-up article will comment on guiding cancer survivors and their family members contemplating dental implant therapy. Pertinent questions, in particular 3 and 4 are:

1. Are cancer survivors candidates for dental implant treatment?
2. If so, what are some caveats and clinical considerations that are unique to cancer patients, which must be considered to ensure safe and predictable treatment outcomes?
3. How do I find the right dentist, one that is trained in performing dental implants

for patients that had radiation, chemotherapy, and other cancer treatment modalities?

4. Are there any ways for dental implants to be more affordable for cancer patients and survivors?

Finding the right dentist who can provide dental implants for cancer patients and survivors

How does one find the right dentist that can treat cancer patients and survivors? Many cancer survivors often have to be creative in finding a dental professional with training in managing disease and treatment-related complications and sequelae associated with chemotherapy, radiation therapy, surgical resection, and/or tissue transfer combining bone and associated blood vessels and soft tissue.

You can stay with your dentist if he/she meets all or most of the following criteria:

- A. completed residency training in a hospital that manages cancer patients (more common than finding an actual dental oncologist)
- B. trained in dental implant placement and management, either through a formal residency or through many hours of continuing medical / dental education (and possible board eligibility or certification)
- C. is affiliated with an academic institution, which enables access to multidisciplinary care with other specialists such as head and neck surgeons, medical oncologists, radiation oncologists, oncology nurses, speech/swallowing therapists, social workers, etc. This is important because risk assessment for dental implants (e.g., radiation dosage received to a particular area of the mandible?) cannot be obtained by a dentist unless he/she directly reaches out to a radiation oncologist/radiation therapist and knows how to interpret those records (e.g., dose maps)
- D. is currently accepting cancer survivors as new patients, regardless of date of diagnosis.

One way is to look up a new provider is to simply search for "dental oncologist near me" or "maxillofacial prosthodontist

near me” via a search engine like Google. Another way is to ask your general dentist if he/she is aware of dental specialists, including oral oncologists, that the office refers to for those who have been treated for oral and head and neck cancer. Finally, if you are really stuck, please consider reaching out to me directly and I’m happy to help search for dental oncology professionals near you.

Are there any ways
for dental implants
to be more affordable
for cancer patients and survivors?

If you happen to be geographically close to certain cancer centers, there may be several dental oncologists who received specific postgraduate training in dental oncology and/or maxillofacial prosthetics from prominent cancer centers such MD Anderson (TX), Memorial Sloan Kettering (NY), Mayo Clinic (MN, AZ, FL), Johns Hopkins (MD), Dana Farber (MA), etc. While there are several hundred dentists who’ve completed dental oncology training in these cancer hospitals, many are in academia (i.e., teaching in universities or hospitals) and/or working directly in said cancer hospitals, which makes it difficult to obtain dental care for cancer survivors (i.e., cancer centers focus on providing dental clearance for those preparing for radiation or chemotherapy, and may not have the bandwidth to take on survivors who’ve already completed cancer treatment).

If you have a dental oncologist or dentist trained in dental oncology in private practice, then he/she is more likely to consider providing implants for you regardless of the number of years

that have passed since you completed chemotherapy or radiation.

If you are out of luck finding an appropriately-trained dentist near you, please consider looking up the nearest NCI-designated comprehensive cancer center and inquire whether there is a dentist that works there. The National Cancer Institute (NCI) has designated 71 cancer centers across 36 states and the District of Columbia, of which 53 are called ‘comprehensive.’ Some have dental departments. Most have relationships with area dentists that they refer to for dental clearance prior to cancer treatment. Such dentists may be able to help.

In summary, my recommendation is to seek services from an experienced dental provider with postgraduate training in a hospital setting with an oncology section. If you really need help finding someone, I’m glad to extend help personally.

*Tips to make dental implants more affordable
for cancer patients and survivors*

Dental implants are expensive. A single tooth replacement using a dental implant costs approximately \$3500-6000 on average in the United States, which involves:

- D6010, the implant surgery visit itself, or the actual titanium screw that goes into your jaw bone
- D6104, bone grafting at the time of implant placement (or additional codes if you need bone grafting before and/or after the implant surgery)
- D6056 or D6057, the abutment, or the component that connects the titanium screw to the final crown
- D6058, the final implant crown (there are other codes for different types of implant crowns)

If you add up the 5 codes above, as well as other possible procedures (e.g., sinus lift, ridge augmentation, platelet-rich fibrin, etc.), the costs can really add up! Please don’t forget that an implant involves 3-6 months of healing (osseointegration of the titanium screw in your jaw bone) as well as multiple peri-operative visits (i.e., x-rays, scanning, stage II/uncovery, impressions, temporary try-in, etc.).

Unfortunately, even private dental insurance plans (e.g., Delta Dental PPO, MetLife, Blue Cross, etc.) that cover dental implant procedures are limited by annual maximums, which often range from \$1000 to \$2500 per annum. Let’s imagine that your Aetna PPO dental plan has an annual

maximum of \$1500. This means that even if 100% of “implant-related procedures” were covered under your policy, every dollar in addition to \$1500 is out-of-pocket cost for you as the patient. If your dentist charges \$4800 for the package of codes mentioned above, that means your out-of-pocket payment will be approximately \$3300 for a single tooth replacement via implant therapy.

If you’re missing 3, 5, or even 20 teeth, then the costs can really add up... and many cancer patients are often missing multiple teeth in both arches. Full-mouth reconstruction using implants can often cost upwards of \$50,000 or more without “help” from dental or medical insurances.

No wonder implants are concurrently the most desired procedure by patients and yet the most out-of-reach for so many patients with complex dental needs!

The key to making implants more affordable is to find an experienced dental provider offering the following options:

- In-house payment plans → because dental implant procedures often take 6 months or more, some practices will allow the patient to pay over time
- External payment plans (e.g., CareCredit, Proceed, Sunbit Finance, etc.) → these outside credit-cards or financing programs allow longer (e.g., 12-60 month) payment plans, but they have interest and patients are qualified based on credit scores
- Digital technology → practices that have intraoral scanners, CBCT machines, milling machines, and/or 3D printers under one roof can provide surgical and prosthetic options more efficiently, which offers savings for the dentist → sometimes, these savings are passed on to the patient (but not always)
- Implant training programs → some dentists teach implants to other dentists, which means they recruit real patients as live surgery candidates → sometimes,

these patients are provided free or discounted fees to receive dental implants

- Medical billing → while many dentists accept dental insurance, the great majority do not “accept” medical insurance... however, with a bit of help, many dentists can utilize medical billing services to collect several thousand dollars for certain patients needing oral surgery and dental implants

The last bullet point above, medical billing, is a very promising yet frustrating element of this puzzle. Medical insurance (e.g., your general health insurance, be it private or federal or some other form) often pays something for oral surgery procedures, including extractions, bone grafting, and alveoloplasty. Sometimes, Medicare alone (which every American 65-years-old and above has) will pay \$2000-3000 for extractions and bone grafting alone! Imagine that a dentist provided implant treatment for you at \$5000, but that \$2000 was accepted via Medicare and \$1500 was paid via PPO dental insurance – potentially, your out-of-pocket cost would decrease to \$1000 from the original \$5000. That makes implants significantly more affordable.

For example, if you are over 65 years old and thus have Medicare (but do not have a HMO dental plan) + you visit a dentist experienced in billing medical insurance + you have an appropriately dentist trained in oncology and implantology, you can potentially save thousands of dollars on every implant!

Please note that this is a “work in progress.” For many decades, most dentists were happy to charge fee-for-service for their procedures or accept private dental insurance (e.g., PPO) to help defray costs for patients. As many patients have noticed, many dentists who provide advanced procedures such as implants do not accept public insurances (e.g., Medicaid or Medicare) or low-paying insurances (e.g., HMO, DMO, DHMO) because they did not have to. For the first 5-7 years of my career practicing dentistry, I did not even know that dental procedures were sometimes covered via medical insurance. It is only in the recent past that I really started exploring this option as a way to help patients financially. And, medical billing requires more work for the dentist, in the form of writing narratives, writing medical

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SOAP notes instead of simpler dental progress notes, talking to insurance reps, learning medical coding (which is significantly different from dental coding), etc. However, I personally hope that there will be a movement towards dentists that participate in medical billing as a means to help patients better afford expensive dental treatment, including dental implants. If done right, it will be a financial benefit to the patient as well as the dentist owner.

Please also note that besides Medicare (e.g., for those of you under 65), private medical plans will sometimes cover dental procedures if the insurance company deems the dental procedure to be related to your medical condition (e.g., cancer or cancer treatment). However, this is never a guarantee, as both medical and dental insurance plans often will deny coverage unless many rounds of appeals and narratives and discussions come into play. The medical insurance may say that the problem is a dental one, whereas the dental insurance will say that the problem is a medical one (e.g., it's because radiation destroyed the salivary glands and caused the cavities). Additionally, dentists with

busy practices often do not have the time (nor feel the necessity) to go “above and beyond” to fight with insurance companies and advocate for their patient in this circumstance. Hence, a dental provider or dental oncologist with significant experience and exposure to the unique needs of cancer patients and survivors (e.g., clinical, financial, chronological, etc.) may be more likely to engage in medical billing to help patients with their overall biopsychosocial needs).

Editors Note: Editor's Note: Dr. Ryan S. Lee, DDS, MPH, MHA, FICOI, FAGD is a dual-fellowship trained dental oncologist in the fields of oral implantology and general dentistry. He is Founder and CEO of Morning Calm Dental Management, a group of 4 practices in NY, MA, RI, and CT that is dedicated to the dental care of cancer patients, survivors, and their family members. Dr. Lee graduated with honors from NYU College of Dentistry, followed by a general practice residency at Jersey City Medical Center and a 2-year surgical fellowship in Dental Oncology at Memorial Sloan Kettering Cancer Center. He has taught as a faculty member at NYU and also served as Department Chair of Dental Medicine in hospital/academic settings in Cambridge, MA and Providence, RI. Dr. Lee's private practice in midtown Manhattan, New York Center for Dental Oncology, was the first-ever private dental practice dedicated to dental oncology in the Northeast and still accepts new patients.

From the Desk of Jack Mitchell

Chapter Facilitator, SPOHNC UTSW

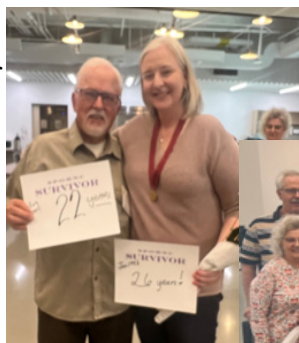
This month's SPOHNC/UTSW Cancer Support Team meeting focused on the awesome Caregivers who got us through our Cancer Journey. We had 9 survivors and 13 caregivers in attendance.

Refreshments of punch, cookies, cake, and fresh fruit were served for all to enjoy. During the celebration, each survivor introduced their Caregiver/Caregivers and spoke a little about their journey, giving their caregivers praise for their assistance on their journey. Following that, Caregivers were given an opportunity to share their involvement in assisting their Survivor with the journey.

Each Caregiver received a rose bouquet and a SPOHNC pin, along with thanks from their

Survivor. Survivors each received a SPOHNC wristband. The survivors ranged in length from 26 years to just completion of treatments. Catie, our contact at UTSW was the longest survivor at 26 years followed by myself at 22 years. She was treated at the age of 17 years old. Todd just completed his treatment less than a year ago.

We plan on making this a yearly event for April. A good time was had by all!!



Massachusetts Oncology Patients, Survivors and Supporters (MOPSS) Update



CALLING ALL MASSACHUSETTS HEAD AND NECK CANCER SURVIVORS!!

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

Massachusetts Oncology Patients, Survivors and Supporters (MOPSS) is working with elected representatives in Massachusetts on Bill #1094 which if passed, would require insurers doing business in Massachusetts to cover medically related dental treatment. This effort is currently being endorsed and fully supported by SPOHNC, and its Massachusetts

Chapter Support Groups, as well as Dana-Farber Cancer Institute, Mass General Brigham, the Massachusetts Society of Otolaryngology/Head and Neck Surgery, the Massachusetts Society of Clinical Oncologists, Mass General Brigham – Mass Eye and Ear, UMass Memorial Health and Massachusetts General Hospital Division of Dentistry. We expect this list of supporters to grow as our outreach continues.

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

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

If you live in Massachusetts and would like to join the MOPSS Committee, we are actively seeking more committee members, so that our voices will be heard! Please contact Tom Healy at THealy1019@gmail.com or by phone at 781-686-3774 for details about upcoming meetings, and how you can help!!

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

The logo for EMD SERONO, featuring the words "EMD" and "SERONO" in a bold, purple, sans-serif font. The letters are thick and blocky, with a slight shadow effect.

EMD SERONO has a long-standing legacy of making a difference in the lives of patients and their loved ones.

Helping to create, improve and prolong lives fuels our passion.

Legacy of a Life Interrupted

A sibling is a friend for life, someone who walks alongside you. Someone who knows the past you had, shares more than a gene pool. Someone you create memories with and if younger, someone who outlives you. I lost my younger and only sibling, Dr. Manu Dua, to Oral Cancer. On that present of March 14th, 2021, I lost the keeper of my past and a part of my future.

Manu was a Dentist like myself. In June 2019 he had a showed me (via text as I reside in New York) a lesion on the side of his tongue that was increasingly becoming painful and discomfoting. He was under the care of his Oral Surgeon, who said it seems like Lichen Planus and was given steroids, but no biopsy. Manu later had his wisdom teeth removed but no biopsy. Later that month he turned 33. I visited him in July 2019, the lesion was now extending half his tongue, brown and leathery in appearance. He had trouble talking and chewing. Later that month, he finally got the biopsy of Stage 2 Squamous Cell Carcinoma with lymph involvement. Manu was a young man, prime of his life with the thriving start up Dental practice in Calgary, AB. A person who was a happy go lucky, healthy, non-smoker and a social drinker. He had no predisposing conditions of Cancer, and was at peak of his life. Cancer diagnosis was not what he was anticipating. When I asked him to biopsy sooner as it looks suspicious for cancer, he said it can't be cancer. I am in my 30s and I am healthy. Like many young people, he thought he was immune to Cancer. It happens to others not me; Manu was in denial or egoistically in his thinking.

Manu did have an 8-hour surgery, removal of half his tongue and reconstruction. He went back to private practice within few months of healing. However, the cancer did have effects, he was easily tired and had trouble focussing. Unfortunately, within 8 months of diagnosis, his cancer had returned. As the world made sense of COVID 19, Manu underwent another surgery followed by 6 weeks of chemo/radiation

in the summer of 2020. His 34th birthday was celebrated in the midst of cancer treatment and COVID. I didn't get to see him during treatment, I watched on the sidelines as borders between US and Canada were shut. I watched my elderly parents nurse their youngest, taking him to doctor visits, getting to chemo/radio/immunotherapy appointments. Getting him the food he wanted, his medications anything to help their only son. Manu recovered well after chemo/radiation and started to live life on his terms. He sold his practice and focused on his health. He started to kayak, golf and go for drives. Unfortunately, in December of 2020, he was admitted due to failure to breathe, he had fluid in his lungs. PET scan revealed metastasis in the lung lining and to his pelvic bone. It was deemed inoperable and Manu was put in palliative care.



The following months were heavy on our family. My parents watched their once vibrant son deteriorate in front of their eyes. With Covid restrictions, Manu went to treatments alone. There were no hugs, no holding hands during treatment. It is hard to imagine is mental strength to undergo rounds of treatment. He knew he was on borrowed time with limited strength to do anything. He had found solace in writing. He never complained about the hand fate dealt him and had made peace with it. He wrote a series of blogs as he battled the disease he was trained to diagnose. These are his reflections of life as he faced his own mortality at age of 34. These are now a book (available on Amazon) called *Life Interrupted, Dr. Dua's Survival Guide* by Dr. Manu Dua.

I did visit him in December 2020 with compassion release granted from the Government of Canada. This was knowing that he was immunocompromised and the risk of COVID was high. What I didn't know that this would be the last time I'd see him alive.

On March 12th 2021, Manu went to the Emergency Room, for a unilateral leg swelling, the next day he was moved to hospice and I was asked to come home. As I scrambled to get my PCR testing, I was asked to say goodbye on a video call on March 14th, as his organs were shutting down. I told him not to wait for me "Go if you need to, you are done fighting. Now rest". In the next few hours, he took his last breaths with our parents by his side. I watched my parents kiss my baby brother's deceased body on a video call. I had not even words to soothe them with or the ability to give a hug or hold

them. I will never know the strength they had to leave him alone in the hospital to be taken to the morgue. To come home alone in the dark, to know that their youngest will never come home.

I did make it to Canada a day later. I was lucky to be there for the funeral during the strict Canadian protocols. I was there for the final goodbye. What someone doesn't tell you about cancer is that it affects not only the person who has it, but the village around him/her. Manu is done with his suffering, but we as a family suffer daily. It was my job to protect him as an older sibling, as a Dentist but I couldn't help him. I couldn't help as a daughter. We suffered the worst diagnosis, in the worst of times under the worst of circumstances.

My hope in sharing his story is that early diagnosis is the key to early treatment and conservative treatment. To pay attention to your bodies and self-advocate as a patient. To have doctors recognize signs and symptoms and screen regularly at check-up appointments. If something doesn't feel right, get it checked out.

Don't treat the symptoms, treat the cause of the symptoms. In other words, unless you have the diagnosis, only then receive the treatment for it. It is hard to watch your loved one die while sitting in the sidelines. I want to share and not have Manu's death be a statistic but a movement in early detection by Dental professionals. A movement to understand risk factors and have ability to do self-checks and get evaluated is something doesn't feel right. A movement in awareness and a movement so that more lives can be saved. A movement so no other has to bury/cremate a loved one due to Oral Cancer.

"...Our lives will come and go, but our ideas will remain immortal, and therefore in essence the soul behind our work remains eternal. So, seek not to fear your own mortality, but rather embrace the challenge to create something that will outlive your fears and wildest imaginations, such that you may be able to provide service years after you have dearly departed. Live with the strength that not only is this not possible, but quiet tangible if we can simply let go of fears that will not serve us with any purpose in this life or next."- Excerpt from *Life Interrupted, Dr. Dua's Survival Guide* by Dr. Manu Dua
Dr. Parul Dua Makkar, is a practicing Dentist at PDM Family Dental in Jericho. She can be reached at parul_dua@yahoo.com. On Instagram @pdmfamilydental.



April Awareness Across the Country

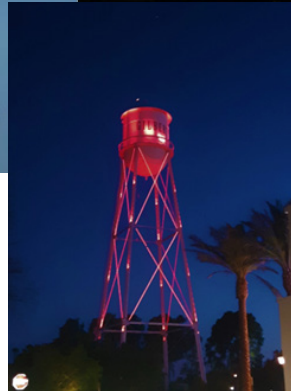
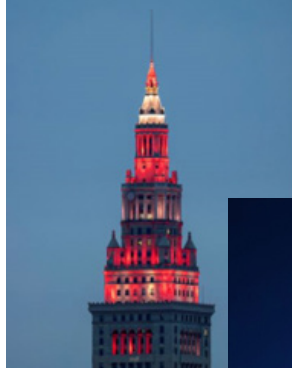
If you're on social media, you've probably been following SPOHNC as we travelled (figuratively, not literally!) from coast to coast, raising awareness of oral, head and neck cancer through our SPOHNC Illumination Family. This year, we were proud to welcome 28 members to our family, with 14 of them being brand new to the cause. Thanks to all who joined us! If you're not on social media, SPOHNC will be featuring the illuminations in eblasts and on our website as well. There have been some pretty amazing photos floating around.

There were also several events held across the United States dedicated to raising awareness, and SPOHNC was proud to be represented, either through survivor participation, or through a table or information shared at the event. Many thanks to Chuck & Jody Bartlett, Hank Deneski, Sabina Omercajic and Stacey Brill, along with



everyone who participated in these events. There have been screenings, community health fairs, and walks and runs too.

If you held an event, or did something special to raise



(photo credit for photo above to SWDF Photography)

awareness in your community, please be sure to let us know, so we can share your news with our readers. It's all about raising awareness, because "Together, WE Heal!"

A Hole in One for SPOHNC

Calling all golfers...especially the ones in Texas. With Spring finally here, thoughts of beautiful green golf courses and dreaded sand traps are on the minds of golfers everywhere. It's time to clean your clubs, brush up on your skills and get ready for two fun days on the links!

The 2023 Annual Rick Agee Foundation Golf Tournament will be held on June 23 and 24, 2023 at the Cliffs Resort on beautiful Possum Kingdom



Lake in Graford, TX. Last year's very successful tournament, attended by 66 golfers resulted in a \$15,000 donation to SPOHNC. The Foundation also supports a college scholarship in Rick's name.

If the 2022 and all prior events are any indication of how great the event will be, you should reach out to Jack Mitchell now to reserve your foursome. There is already a core group that attends each year, so you don't want to miss out. For more details and information, reach out to Jack Mitchell at jackmitchell5225@aol.com. Fore!!

"I feel very blessed to have found you..."

~ David

Am I a Member of SPOHNC?

If you have ever called us, e-mailed us or have ever been touched by SPOHNC in any way, we like to thank you, by sending you this **complimentary** Spring issue of “News from SPOHNC.” In fact, you receive another one in the Fall...but if you are not a SPOHNC member, *you are missing out on 6 additional issues.*

**As a SPOHNC member,
you receive
8 issues per year.**



*Become a Member! Renew Your Membership!
Gain These Benefits*

- Are you still dealing with side effects of treatment? SPOHNC’s 44 page PRODUCT DIRECTORY is full of product suggestions and how they can help you. This book is a must for anyone seeking relief.
- “News from SPOHNC” features articles written by highly respected healthcare

professionals, sharing stories written by survivors, current head and neck cancer news, survivor and chapter news, human interest stories and more.

- Access to SPOHNC’s more than 100 Chapter Support groups.
- Access to SPOHNC’s National Survivor Volunteer Network of more than 225 survivor and caregiver volunteers, ready and willing to serve as a mentor to a newly diagnosed patient or caregiver.
- Opportunities to connect with patients and survivors. Contact SPOHNC to find out how.
- Insider information about special programs and resources. You will be the first to know.
- Access to additional resources through direct contact with SPOHNC’s Outreach Staff.

If you haven’t joined SPOHNC as a member, please consider doing so, and gain these “MEMBERS ONLY” benefits offered just for you. Membership is just \$30 annually.

Don’t miss out on some great resources that have been designed with care, to help you. We are here to support you, because “Together, WE Heal!”

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Are you a cancer **SURVIVOR** suffering from dry mouth?

Learn more about our radiation-induced xerostomia clinical trials:

www.meiragtx.com/patients-families

Eat Your Veggies!



Zucchini Ratatouille
— RECIPE —

INGREDIENTS

6 small zucchini, cubed	1 small can tomato sauce
1/2 onion, chopped	Olive oil
2 large potatoes, peeled & cubed	Salt & pepper

.....

Nutritional Information Per Servings:

Calories 700cal, Total Fat 4(g), Saturated Fat 1(g), Cholesterol 0(mg), Sodium 176(mg), Carbohydrate 8(g), Dietary Fiber 2(g), Protein 2(g)

Parboil potatoes & drain. Sauté zucchini & onion in olive oil. Add potatoes to zucchini/onion mix. When all is softened, add a small can of tomatoe sauce & salt & pepper to taste. Simmer for 30 minutes.

Kathy P. - NJ

SPOHNC's RESOURCES

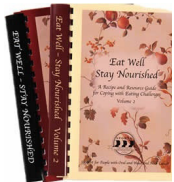
We Have Walked In Your Shoes: A Guide to Living With Oral, Head and Neck Cancer
- by Nancy E. Leupold & James J. Sciubba, DMD, PhD

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PRINT EDITION \$14.95 includes shipping and handling



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Eat Well Stay Nourished
A Recipe and Resource Guide for Coping With Eating Challenges
compiled by Nancy E. Leupold, Founder



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With Gratitude

SPOHNC would like to take this opportunity to recognize and celebrate our volunteers! Our “Champions of Hope” volunteers have been serving patients, caregivers, and their families since 2004 bringing them the opportunity to share diagnosis and treatment experiences as “someone who has



walked in your shoes.” On behalf of SPOHNC, we want to thank each and every one of you who have displayed courageous and selfless caring for those that needed it the most.

SPOHNC’s National Survivor Volunteer Network (NSVN) has been matching newly diagnosed patients and those going through treatment with survivors of oral and head and neck cancer since 2004. With 225+ volunteers and a matching program, SPOHNC will connect you or your loved one with a survivor or caregiver volunteer according to diagnosis and treatment plan, so that you can speak to someone who has “Walked in Your Shoes.”

For more information, please contact our office at 1.800.377.0928 or email us at info@spohnc.org.

Spring Champions of Hope

Jack and Maryellen Mitchell

April Awareness Month and Springtime celebrates “a couple” of the friendliest, most hospitable, and supportive members of our SPOHNC family – Jack and Maryellen Mitchell! Jack and Maryellen found SPOHNC in 2002, and they have been a very important part of our SPOHNC family ever since.

They became SPOHNC members in 2003 and continue to support us through their own kindness and generosity, as well as the many events that they have put together, volunteered for and contributed to, making each one very successful. They are both experts in the field of volunteering!

Jack has been the Facilitator of several SPOHNC Chapter “support teams” as he calls them, in the Dallas area, for many years. His ability to secure speakers for meetings on topics of great interest, goes unmatched. He taps into the facilities where the meetings are held and always finds experts in the field. Some of the topics covered have included art and music therapy, dental needs for head and neck cancer patients, and speech and swallowing as well. Jack has even supplied our **News from SPOHNC** newsletter with an important article about *Holiday Eating Tips*, which we have shared a few times over the years. Jack is also great about helping those in the group who may have specific questions, reaching out to SPOHNC and others for support when the need arises.



Jack and Maryellen have been an integral part of many awareness events and screenings, including Rick Agee’s Skate 4 SPOHNC, the Memorial Rick Agee Skate/Walk/Run for SPOHNC, the Park Bench Dedication, held in honor and memory of our dear Rick Agee, who passed away in 2015, and now the Annual Rick Agee PK Memorial Golf Tournament. SPOHNC’s Founder Nancy Leupold, and Executive Director, Mary Ann Caputo both attended the first Memorial Skate/Walk/Run for SPOHNC, in April 2015, and Jack and

Maryellen made it a family affair when their daughter, Allison, hosted everyone for dinner, sharing her culinary skills with a wonderful meal! Mary Ann and her husband Larry, have also attended the Golf Tournament, where Larry supported a foursome with his excellent golfing skills. At the awards ceremony Mary Ann spoke about Rick, his infectious personality, and how he drove from Dallas to New York just to visit his SPOHNC family. She spoke about SPOHNC’s mission and how the golf outing fundraiser benefits many patients through SPOHNC’s programs and resources. Mary Ann thanked the entire Agee family for all their support and dedication and for continuing Rick’s legacy.



Jack and Maryellen served as most gracious hosts to Mary Ann and Larry, inviting them into their beautiful home in Little Elm, Texas. They opened their hearts and shared their lovely, serene surroundings, as well as some fun activities and great restaurants with their guests, always making them feel special and right at home, with their trademark southern hospitality. In the past, Jack and Maryellen have also made the trip from Texas to New York to attend and support SPOHNC’s 15th Anniversary Conference in 2006 and the 20th Anniversary Conference and Celebration of Life in 2012, joining us along with several hundred patients and survivors for some days full of learning, support and celebrations as well.

Jack is a busy man. Not only does he help to guide and inspire patients and survivors through the support teams, he is also an avid hunter, fisherman, gardener and a bee aficionado. Where does he find the time? He is also a super proud family man, with children and grandchildren across the country, which he and Maryellen visit as often as they can. Oh – and did we mention he is a sports fan as well? Jack never misses a chance to razz us in the office about our beloved Yankees or NY Giants!

Jack and Maryellen’s passion, compassion, leadership, commitment, focused vision and the way they engage “support team” members through constant communication, are just a few of the qualities that make them such wonderful and valued members of our SPOHNC family. They are forever dedicated to helping those who have been affected by the diagnosis and treatment of oral, head and neck cancer, and we know they will never stop.

Jack and Maryellen, we know “everything is bigger in Texas” so we know your hearts are as huge as your commitment to SPOHNC. We are forever grateful for your friendship, your devotion and the enthusiasm that you share with others when it comes to support. It is contagious! We are honored to call you our Spring 2023 Champions of Hope, as you continue to raise awareness and support the mission of SPOHNC. Thank you, from the bottom of our SPOHNC hearts, for all you do!

Head and Neck Cancer News

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

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

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

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

Share your experience living with Head and Neck Cancer

IQVIA

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

SCAN HERE TO SEE IF YOU QUALIFY

**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



Support for People with Oral and Head and Neck Cancer, Inc. is grateful for the generosity of its contributors. Thanks to their support, SPOHNC is able to maintain and extend its programs of education and support to cancer survivors, their families and friends. With sincere appreciation to all.

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BioNTech is committed to improving the health of people worldwide with our fundamental research and our work in the area of development of immunotherapies utilizing the full potential of the immune system to fight cancer, infectious diseases and other serious diseases.

Eisai believes human health care (hnc) is the shared purpose that connects us to those we serve creating a network of powerful relationships that enables us to identify, understand and work to address the needs of people throughout their lives.

EMD SERONO has a long-standing legacy of making a difference in the lives of patients and their loved ones. Helping to create, improve and prolong lives fuels our passion.

Galera Therapeutics is discovering and developing novel mechanism-based therapies that have the potential to improve both treatment and outcomes for patients with cancer.

MeiraGTx is a clinical-stage gene therapy company focused on developing potentially curative treatments for patients living with serious diseases.

Merck uses the power of leading-edge science to save & improve lives around the world.

Naveris delivers disruptive technology with the potential to transform cancer detection & improve patient outcomes.

SQZ Biotech is a clinical stage biotechnology company developing transformative cell therapies for patients with cancer, infectious diseases and other serious conditions.

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All survivors *by Diane Williams*

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Nancy Leupold's Loving Page of Remembrance 2022

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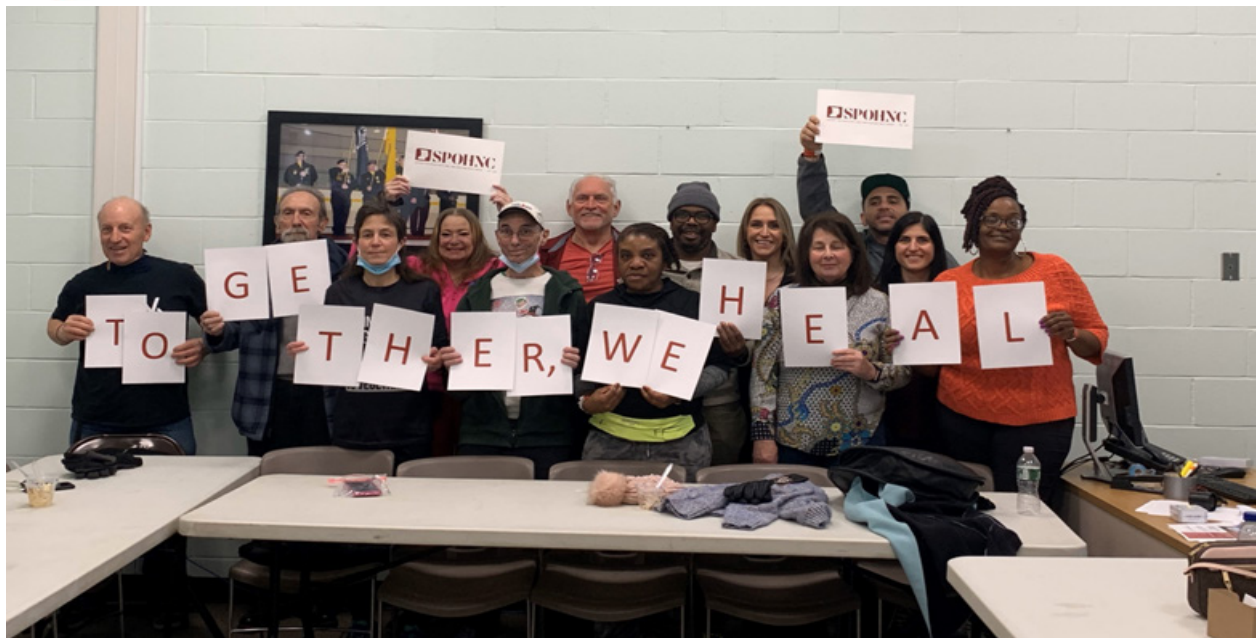
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Contact SPOHNC at 1-800-377-0928 for Chapter information & Facilitator contact information.

PLEASE NOTE: Some Chapters have not yet returned to holding meetings in person at this time.

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

Call SPOHNC to find out more.



Featured above is SPOHNC's Syosset, NY Chapter Support group.

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

SPOHNC

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