



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



35
a celebration
of being alive
presented by katie drablos

Thank you, Katie Drablos for a magnificent performance. Those who attended “35: A Celebration of Being Alive” sat in awe of her strength, creativity, resilience, and talent. What a night!



We loved each performance given by Katie’s fellow dancers, collaborators, cancer survivors, and Katie’s mom touched each one of us through her narrative of Katie’s cancer journey. Thank you, Katie, from the bottom of our hearts for sharing this fundraiser for SPOHNC!

Depression in Head and Neck Cancer Patients

Aru Panwar, MD, FACS
&
Rodolfo Manosalva, MD

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The Elephant in the Room

How do I get him off of me?
Find out on page 6.

Life Can Move Forward

Read about a caregiver who continues to help, even after her own journey takes an unexpected turn. Turn to page 9.

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

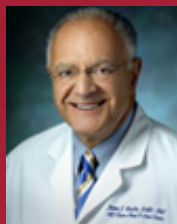
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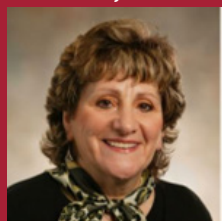
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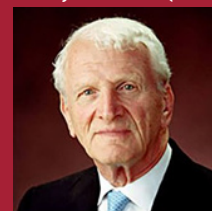
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Chris Leonardis

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Depression in Patients with Head and Neck Cancer

Aru Panwar, MD, FACS
& Rodolfo Manosalva, MD

The diagnosis of head and neck cancer can be a life altering event that may be a source of significant psychological and emotional stress.

In addition to the physical effects related to both the cancer and its treatment, the diagnosis can have a profound psychological impact that may affect patients and their caregivers in a way that is often under recognized or ignored.

Depression affects 1 in 4 patients affected by cancer. It is even more common in patients affected by head and neck cancer with nearly 1 in 2 patients experiencing signs and symptoms of depression. This is not surprising considering how head and neck cancer can affect functions that are essential to everyday life such as eating, speaking, and breathing. In addition, the cancer itself and/or its treatment can lead to disfigurement in a cosmetically sensitive area of the body which can affect how someone perceives themselves and how others perceive them. The effects of depression can be devastating since patients with head and neck cancer who suffer from this condition may experience: three times higher risk of suicide, poor quality of life, higher chance of not completing treatment, and increased risk of death. It is therefore important to be aware of the risk factors for development of depression, the signs and symptoms of depression, prevention strategies, and available treatment.

What is depression?

The difference between feelings that would be considered normal and expected after a diagnosis of cancer and the transition to depression can be difficult to distinguish initially. Some individuals may feel sadness, hopelessness, guilt, and anxiety, for example, when dealing with a potentially life-threatening condition. There are also differences in how someone may react and feel after receiving bad news and when facing adversity.

Depression, however, is a serious mood disorder that consistently and over a prolonged period of time affects

how you think, feel, and behave usually lasting more than two weeks. It is important to keep in mind that signs and symptoms of depression may appear at any time during cancer survivorship which highlights the important role of ongoing awareness, screening, and prevention. Patients, their loved ones and healthcare providers should consider screening for depression and its prevention and management as one critical element of the comprehensive cancer care plan right from the time when cancer related concerns are first identified.

General risk factors which can increase the risk of depression during head and neck cancer treatment include a previous history of depression or anxiety, and addiction to tobacco, alcohol, or other substances.

Other factors that may place patients at risk of developing depression may include: stress related to cancer diagnosis, lack of a social support system, treatment-related side effects, physical disfigurement and loss of self-esteem, loss of function (speech, swallowing, smell, taste, etc.), poor nutrition and weight loss, disruption of daily life patterns, loss of intimacy, disrupted sleep due to side-effects of treatment for cancer (e.g., dry mouth, pain, etc.), and hypothyroidism (low thyroid hormone levels).



What are the signs and symptoms of depression and how is it diagnosed?

It is important that patients with head and neck cancer, their loved ones and healthcare providers remain aware and vigilant about the possibility of development of depression. Signs and symptoms of depression may include: persistent feelings of sadness, emptiness, irritability, or anxiety; feelings of hopelessness or pessimism; feelings of guilt, worthlessness, helplessness, or shame; loss of interest or pleasure in hobbies/activities; decreased energy, fatigue, being “slowed down” (which can also be a side effect of radiation); difficulty with concentration, memory, decision making (also a side effect of chemotherapy); loss of sleep, early morning awakening, oversleeping; appetite and/or weight changes (gain or loss, though weight loss is also a side effect of cancer treatment); thoughts of death, self-harm; suicide attempts; restlessness, and other persistent physical symptoms.



To screen for depression, the healthcare team may ask questions about mood and behavior. They may also request that the patient answer a list of questions used to screen for depression. Due to increased risk of depression and the impact of depression on quality of life for

head and neck cancer survivors, the American Cancer Society recommends that patients diagnosed with head and neck cancers should be screened for depression on a periodic basis, including at the 3-month evaluation after completion of treatment and subsequently, on an annual basis.

In some cases, the patient may be offered the option or be asked to see an expert in behavioral health care for additional evaluation. A diagnosis of depression may be made after a thorough evaluation in patients who meet the diagnostic criteria.

How is depression treated?

Unfortunately, depression is often under-recognized and under-treated. Studies suggest that less than 30% of severely depressed patients are identified and over 70% are inadequately treated when depression is recognized. If signs

and symptoms of depression are seen or suspected, help should be sought. Asking their medical provider for help may be the most appropriate early step for most patients, however, help can take many forms outside of traditional

More recent research
has focused on
the important role
of prevention of
depression

healthcare including talking about it with friends, family, engaging social support, or joining a support group.

The treatment of depression may include a behavioral health consultation, assistance with substance abuse issues, and psychotherapy – a process of learning new skills for coping with cancer and stressors. The American Psychological Association guidelines for treatment of depression recommend a variety of options for initial treatment with behavioral therapy, cognitive, cognitive-behavioral, and mindfulness-based cognitive-therapy, interpersonal psychotherapy, psychodynamic therapy and supportive therapy, which may be utilized with comparable effectiveness, depending on specific patient circumstances, needs, and access to expertise in these techniques.

Treatment of depression may also include antidepressant medications under the supervision of qualified healthcare professionals. In some cases, patients may benefit from a combination of medication and psychotherapy. Other complementary therapy options for treatment of depression may include exercise, St. John's wort, bright light therapy, Yoga, addition of acupuncture to ongoing antidepressant medication use. A discussion with a qualified healthcare provider is essential to determine a treatment plan that best suits the needs of a patient.

Find SPOHNC at www.spohnc.org

More recent research has focused on the important role of prevention of depression in patients with head and neck cancer. Meeting with a medical or behavioral health provider to discuss depression prevention strategies that focus on better ways of coping with the diagnosis of cancer and its treatment is important. Research suggests that antidepressant medications may be useful in the prevention of severe depression in patients newly diagnosed with head and neck cancer who are not depressed at baseline. Initiating antidepressant medication at the time of cancer diagnosis or at initiation of cancer treatment has been shown to be safe and cost effective, reduces the risk of developing clinically significant depression in half, and many patients experience improved quality of life with this strategy. Patients and their healthcare providers may consider this through shared decision making, and while continuing to explore strategies at stress management, identifying improved coping mechanisms, behavioral modification and other useful approaches.

When should a physician or provider be contacted?

A patient may be experiencing depression if they have been suffering some of the symptoms mentioned above on most days for at least two weeks. If you are unsure, but worried about possible depression related symptoms, ask your healthcare team for help. They may be able to effectively screen you for depression and offer treatment if necessary. Patients who are not depressed but exhibit distress related to the diagnosis of head and neck cancer, may consider discussing strategies for preventing depression with their healthcare team, and may explore options including meeting with a trained mental health care professional and discuss role for prophylactic use of antidepressants.

If you need urgent help

If you have feelings of harming yourself or others, or if you need urgent help, please call 911, call the National Suicide Prevention Lifeline at: 1-800-273-TALK (8255) or www.suicidepreventionlifeline.org

Starting July 16, 2022 a new three digit dialing code (988) will be available to everyone across the United States that will route callers to the National Suicide Prevention Lifeline. Some areas of the United States may be able to connect to the Lifeline by dialing 988 before July 16, 2022.

Resources to learn more about depression

- 1) Depression: What you need to know. U.S. Department of Health and Human Services, National Institutes of Health, National Institute of Mental Health. (2015). Depression (NIH Publication No. 15-3561). Bethesda,

MD: U.S. Government Printing Office.

Webpage: <https://www.nimh.nih.gov/health/publications/depression-what-you-need-to-know/index.shtml>

- 2) Chronic Illness and Mental Health. U.S. Department of Health and Human Services, National Institutes of Health, National Institute of Mental Health. Bethesda, MD Webpage: <https://www.nimh.nih.gov/health/publications/chronic-illness-mental-health/index.shtml>

Editors Note: Dr. Aru Panwar is a head and neck cancer specialist at Methodist Estabrook Cancer Center at the Nebraska Methodist Hospital and an associate professor of surgery at Creighton University School of Medicine, Omaha, Nebraska. His clinical work is devoted to comprehensive care for patients with head and neck cancers and he has led research focusing on prevention of depression in patients diagnosed with head and neck cancers and towards development of clinical pathways to enhance survivorship experiences of patients affected by head and neck cancers.

Dr. Rodolfo Manosalva is currently a Head and Neck Surgical Oncology and Reconstruction Fellow at Creighton University School of Medicine - Methodist Estabrook Cancer Center. He received his medical degree from Loma Linda University School of Medicine and completed surgical training in Otolaryngology - Head and Neck Surgery at Naval Medical Center Portsmouth. Prior to entering subspecialty training Dr. Manosalva served as a medical officer in the United States Navy. He is board certified in Otolaryngology - Head and Neck Surgery and belongs to the American Head and Neck Society.

How Can SPOHNC Help You?

Join a SPOHNC Chapter Support Group

Connect with a Survivor or Caregiver Volunteer

“Together We Heal”

Contact SPOHNC today at 1-800-377-0928

or at info@spohnc.org

The Elephant in the Room



He has a habit of following me to each check-up but he doesn't come into the examination room with me. No, the big creep lurks in the background, stalking me until I get home and try to go to sleep, then he sneaks in my room and perches himself right on top of my chest causing me angst and sleeplessness. Nothing I do or say will get him get off of me. He seems to really enjoy making me uncomfortable.

My friends, of course, don't ever see him. They look at me and say, "he's in your mind. If there really was an elephant living with you we would definitely see it". "Oh", I say, "he is there, and he is big, and gray, and smelly, and he is trying to ruin my attempt to live a normal life".

I have noticed that when I talk about him in group, or among friends, he seems to fade into the background, much preferring to torment me when I am alone. That fact gives me hope that one day, maybe tomorrow, or maybe it will be 15 years from now, I will convince him to pack his bags and leave me alone. Everyone says it will happen. But it's been 17 long years of dealing with this big fella and I am somewhat skeptical. That doesn't mean I will ever quit trying. The problem is, I woke up with a really sore throat this morning and when I turned my head and began to rise, he was staring me right in the face.

Mike Greco
mhgreco@gmail.com

Let's drag the big fellow out into the open.

It has been almost 17 years since my treatment ended and I am still sitting in my living room staring at this big geeky elephant. He sits there as I drink my morning coffee and catch up on the news of the day. He doesn't say much, in fact he is eerily quiet. But every once in awhile, when I least expect it, he stirs, the room shakes, and I can hear his trumpet blast, even through the constant ringing in my ears. He rumbles towards me, totally uninvited, and plops down right on my chest. His weight paralyzes me and my breath catches and I wonder if I am going to make it through the next 60 seconds without suffocating. How do I get him off of me? I can't think of anything else for hours, except why does this big pachyderm persist on torturing me? Why is he set on crushing my spirit? I don't want him around. I certainly don't feed him. I constantly yell at him to go away but he doesn't budge.

I am pretty sure he feeds off of the fear in my mind. He must, because he is very fat and shows no outward sign of going away. The doctors say, "we can give you some cool drugs to make him harder to see", but I don't want to live my life in a drug induced euphoria.

SHARE *your*
JOURNEY

with our readers...

Contact SPOHNC today
at 1-800-377-0928
or at info@spohnc.org
to find out how.

Katie Drablos

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 34-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.

Katie Drablos is a dancer, choreographer and teacher of dance. Her Mom connected with SPOHNC, following Katie's diagnosis and treatment, seeking information, support and a connection with those who understood what she was going through. Katie and her Mom found the help they needed, through SPOHNC's programs and services of support.



in NYC with fellow cancer survivors, family and friends and the proceeds from the show benefitted SPOHNC. The audience was filled with emotion as Katie's Mom narrated her entire journey throughout the performance.

Some of our SPOHNC family and staff were honored to be able to attend this beautiful expression of Katie's thoughts and feelings as she told her story, through the magic of movement and dance. The raw emotion that was felt throughout the evening, and learning about her cancer journey, was a humbling experience for the audience members who were there to support Katie and her fellow dancers.



SPOHNC is grateful to Katie, who has shared the video of "35" A Celebration of Being Alive" with SPOHNC.

Katie shared her story during an interview with NBC's Today Show online magazine journalist Meghan Holohan and how she found solace and the strength to press on through music, people, and the healing power of dancing!

Check out our website at spohnc.org, for the link to the video. If you were not able to attend, you can still experience the magic of such a beautiful performance, by such a talented and amazing group of dancers and collaborators.

On April 1st, in celebration of her "35" birthday and being alive, she choreographed and held a dance showcase

Thank you, Katie, for raising awareness, giving back and above all for your immense love.



Do you have a topic of interest that you'd like to see covered in a future feature article in "News from SPOHNC"?

Email us to today at info@spohnc.org.

We want to hear from you!

Research Opportunity

This Clinical Trial Opportunity is being offered by Bonnie Martin Harris, a member of SPOHNC's Medical Advisory Board

Are you a head and neck cancer patient or survivor?

Dr. Bonnie Martin-Harris, a member of SPOHNC's Medical Advisory Board, and her team at Northwestern University are currently conducting a variety of swallow-related clinical trials for head and neck cancer survivors. The studies take place in Chicago, but there are some studies that would be feasible even for those living outside of the Chicago area.

Email the Swallowing Cross-Systems Collaborative
Lab at: scsc@northwestern.edu
for more information and referrals.

Now Recruiting



Clinical Trials for Patients with Head and Neck Cancer

Dr. Bonnie Martin-Harris and her team are studying a new swallowing therapy to improve eating, drinking, health, and quality of life of individuals with head and neck cancer.

Inclusion Criteria

- All patients who were diagnosed with primary head and neck cancer *at any point in their lives* (recently or long-time ago), had or continue to have swallowing problems can contact us to inquire about the swallowing rehabilitation clinical trials.
- Patients who underwent any type of cancer treatment (surgery, radiation, chemotherapy or any combination) may be eligible.
- Patients with or without current swallowing problems may be enrolled if they meet all study criteria.

Participants will be compensated for their time. Study visits will take place in the greater Chicago area.

Please contact the Swallowing Cross-Systems Collaborative Lab for more information and referrals:

Phone: 847-467-7447 or Email: scsc@northwestern.edu

For more clinical trials,
please visit
SPOHNC's website at
spohnc.org, and go to the
Cancer Information tab.



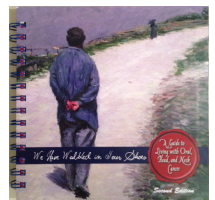
Through SPOHNC,
Carebox can help you
find the information
you need.

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

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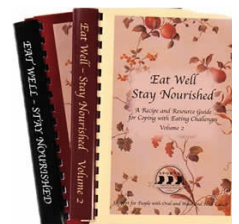


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Caregiver Champion of Hope

Kathleen Dicedue

Our Summer Champion of Hope
is truly
an unsung hero...



In the eyes of the SPOHNC family, Kathleen Dicedue, RN, MSN, geriatric nurse practitioner, wife, mother, and National Survivor Volunteer Network caregiver volunteer, is truly an amazing woman.



Her husband, Robert, was diagnosed in 2002 with unknown primary cancer of the head and neck, and while tending to her husband's needs, she joined SPOHNC as a caregiver volunteer, ready to help the many caregivers who connect with SPOHNC seeking someone who understands what they are feeling, and needs the compassion of a fellow caregiver who has walked in their shoes.

Kathleen shared her heart wrenching story in the April 2007 issue of "News from SPOHNC." In her story, she shared Robert's cancer journey, from diagnosis through treatment, and eventually, his passing in 2005. Her poignant words detailed their last moments together, and you can truly feel the love, compassion and the heartbreak, all at the same time. She wrote the story as part of her therapy along the journey, and she felt that it was important for others to know that you can make it, even through the darkest of times.

Kathleen made the decision to stay on as a caregiver volunteer following Roberts passing, and she remains steadfast in her commitment to this today. Her unique experience has served as a compassionate guide for many spouses who never thought that they would be witness to their loved ones end of life journey. Kathleen has the experience to take someone by the hand, and walk them through the darkness, and back out into the light. She is living proof that life, though very different, can move forward.

SPOHNC owes a special debt of gratitude to this incredible woman, who gives of herself and her experience, and stays connected with all of those that SPOHNC has matched her with along the way. This group of spouses shares an unimaginable bond, and they lift each other up to carry through their days and nights, and their lives, even without the companionship and the love of the ones they have lost.

We look to you with grace and gratitude, Kathleen, and we honor you as our Summer issue Champion of Hope. Simply put, thank you...our hearts are full...

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Lincoln, Nebraska Raises Awareness

SPOHNC's Lincoln, Nebraska Chapter support group recently participated in Lincoln, Nebraska Balance,

Mobility and Cancer Rehabilitation's first ever free community oral cancer screening clinic. The group attendees that helped were glad to be a part of this inaugural effort – and an in-person event!

The screening was held on April 2, 2022. Participating organizations included a school of dentistry, ENT's, cancer nurse navigators, Aging Partners in Lincoln



and the Heartland Cancer Foundation. There was a table of information about SPOHNC and the local Chapter attendees staffed the table for the day, answering questions and providing literature for those who wanted to know more about SPOHNC's programs and services of support.

There were 32 people screened and 3 people had concerning lesions with another 4 needing dental follow up. They were given a list of providers and then they were called to make sure they were being linked in with someone for further evaluation. The group plans to do this on a yearly basis and they said they're excited if they caught even one person early!

Thank you to organizers Polly Ubben, Chapter Facilitator, Regina Edington, Chapter Co-Facilitator and Support group attendee and NSVN volunteer, Scott Wieskamp, for raising awareness, and for sharing these great photos!

On The Road Again!

June 3rd through 6th was a busy weekend in Chicago, which hosted the 2022 American Society of Clinical Oncology Annual meeting. SPOHNC's Executive Director, Mary Ann Caputo, and Outreach Administrator, Chris Leonardis, were just 2 of about 30,000 attendees at one of the largest international oncology conferences in the world, held at McCormick Place. It was great to be back in person, and have a chance to reconnect with colleagues while discovering the latest cutting-edge research in cancer care.

SPOHNC was honored to be part of the Patient Advocacy Pavilion, where more than 35 patient advocacy groups across all types of cancer support joined us to share their resources as well. Conference visitors stopped at our booth to hear about SPOHNC's programs and services of support, view our publications, and have some chocolate and receive our takeaway gift, which was a SPOHNC pen this year. They were very popular!



well...the conference center is huge so there was lots of walking involved as we visited other booths and spoke with researchers who are doing studies or developing new treatments and products for oral, head and neck cancer patients and survivors. This year, we were surprised that so many attendees who came to our booth were also survivors who want to join our programs as volunteers.

Mary Ann Caputo was also honored to meet the incoming President of ASCO for 2023. ASCO has elected Lynn M. Schuchter, MD, FASCO, a long-time member and volunteer, to serve as its President beginning in June 2023.

SPOHNC's dear friend, Julie Aguirre-Garcia, a longtime Chicago resident and healthcare professional who works at Lurie Children's Hospital in Chicago, has helped us at our booth for several years now. She is a kind and caring soul, assists us with our Spanish speaking visitors at our booth and is very handy when it comes to knowing where to go and what to do in Chicago...if we had the time!

ASCO is wonderful exposure for SPOHNC and it gives us a chance to network with others, identify potential corporate partners and meet new friends too. Believe us when we say we logged some serious foot miles as

SPOHNC always gains valuable information at ASCO, and we were excited to be selected by ASCO to be there, and share our mission and Nancy's vision with all who attended, from all over the country, and the world!

CHAPTERS OF SPOHNC

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

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

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

Call to SPOHNC to find out more.



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

SPOHNC
1-800-377-0928 or info@spohnc.org
spohnc.org



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HEAD AND NECK CANCER | EST. 1991

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help you.

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SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER (SPOHNC)

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