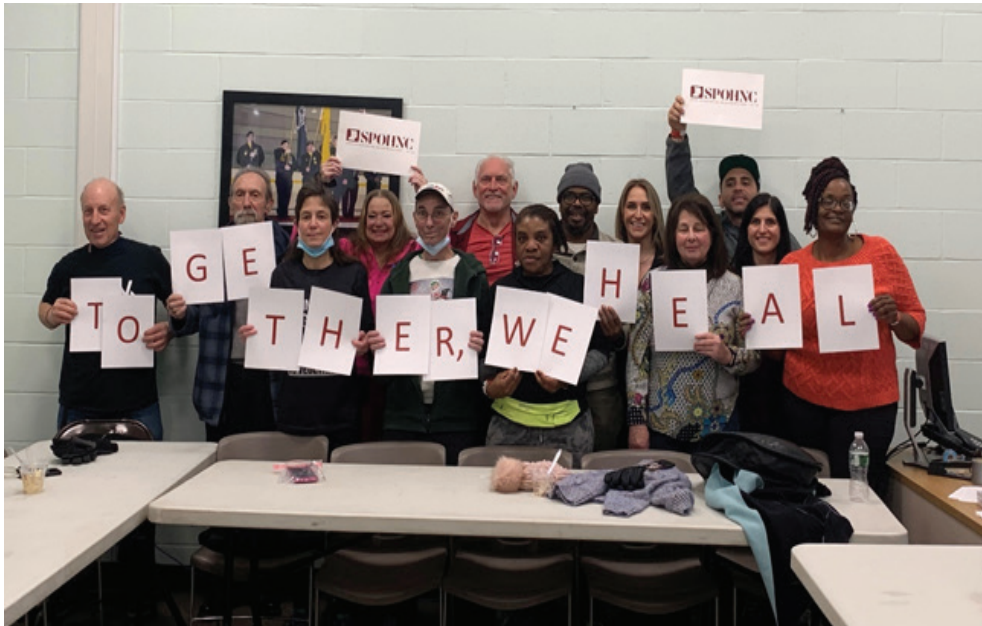




SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER | EST. 1991



“Together,  
WE Heal”

SPOHNC’s Syosset, NY Chapter Support group is at it again.

The Winter outing was held at a local indoor ice skating rink. A good time was had by all!!!

## April Awareness Approaching

Read more on page 6.

## Survivor and Chapter Happenings

Find out more on page 8.

## SPOHNC Salutes You

Read about a couple who faced the cancer journey together. Turn to page 10.

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## Talking to Your Kids About Your Cancer Diagnosis

Mike Ellis, LMSW

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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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# Talking to Your Kids About Your Cancer Diagnosis

Michael Ellis, LMSW

No one knows your children better than you do.

Receiving a cancer diagnosis is challenging for patients as well as their family. Children are not immune from the impact of a cancer diagnosis for their parent or an adult family member. According to a 2017 study in *Anticancer Research*, 22.4% of cancer cases occur for individuals aged 21-55. In other words, nearly 3 million children under age 18 will have a parent who is diagnosed with cancer.

“Over the last 30 years, overall cancer survival rates have increased with the five-year survival rate rising 20% across all races,” the study notes. Studies have suggested that children of cancer patients are impacted and have a higher risk of emotional and behavioral issues. What we do to support children in these situations is important.

Patients face many stressors when finding out they have cancer, and perhaps one of the most stressful situations is figuring out how to share the news of a diagnosis with your family—particularly children. It is important to keep children in the loop throughout diagnosis, treatment, and recovery. No one knows your children better than you do. This information is meant to assist you as you adapt to the role of patient and include your children in this journey.

Newly diagnosed parents often have questions about how to talk with their children about their

diagnosis. What we do as adults as we approach this question will influence the children for a lifetime. Children rely on their parents to keep them safe and to protect them, but protecting our children does not mean that we should shield them from the truth. Maintaining an honest and supportive relationship with our children is important to ensure they can adjust to any changes that may follow.

While talking about a cancer diagnosis can be tough, striking a balance between open communication and easing a child’s worries and fears can be especially challenging. It will be important to keep the children in the loop throughout the diagnosis, treatment, and recovery period, communicating with them consistently as the treatment and recovery ebbs and flows. There is never an easy and straightforward map that outlines a sure-fire path for treatment of any cancer.

Use terms that you hear at visits with your doctor to ensure that your children are not misinformed. It is important that they remain informed, and that they do not have doubts or fears about being kept in the dark. We need them to continue to trust and engage with the adults in their life to ensure that they can focus on childhood and normal development.

Honesty is vital in maintaining the trust and relationship with your children. Explain your diagnosis to your children, and let them know the doctors are doing their best to take care of you. Answer questions that the child may be asking. Be specific - tell them what type of cancer you have, and what type of treatment you are getting, using terms your providers use, geared toward the age of the child. Do not shy away from using the word cancer. Again, remember we need them to trust us as adults, and if they suspect that we are trying to hide something or that we are not being honest, this will sew doubts in their minds. Communicate with them



about how often you will be treated and how this treatment will help. Again, use language used in the doctor's office. Tell them about next steps throughout the treatment. Confirm that you will continue to update them as you learn more and that they will be involved every step of the way.

Fear is a common reaction to learning of a cancer diagnosis, and children may have many questions. Therapists say one of the first questions pre-teens ask is, "Are you going to die?" How you answer these difficult questions will set the standard for how your family will handle difficult situations. Children react to the news of a cancer diagnosis in many ways.

While you cannot promise or guarantee a specific outcome, you can promise that you are in the care of an excellent team and that you are receiving very powerful treatments that are working to treat the cancer. Let them know that you will continue to keep them involved in your care and that they are free to ask questions.

Cancer treatments have many side effects, such as hair loss, nausea, and fatigue. In some cases, the patient will have to be hospitalized for their care. As parents, it will be important to tell our children about the potential side effects of treatment so they know what to expect. Encourage them to be involved at their own comfort level.

If a parent has a prolonged hospital stay, allow the children to help decorate the hospital room. Set up a routine for "virtual visits" through Skype, FaceTime, or Zoom. The pandemic has taught us all that virtual tools can allow us to remain connected with family, friends, work and school from afar.

If you experience hair loss, consider having a hat or a head-shaving party to help children confront their fears of mommy or daddy being bald. Children can help with chores around the house or cooking dinner, but not all children will want to be involved at this level. Allow children the time that they need to process information and ask questions at their own pace.

Talking to your children about a cancer diagnosis is not easy, but the good news is that children are very resilient. Open communication helps to ease their fears and concerns and can be very helpful throughout this difficult time of transition. As a parent, this can seem to be a daunting prospect to broach a discussion about cancer with your children. Supports are available to help you as you contemplate initiating this discussion. The social worker in your clinic is a good starting

Talking to your children  
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point. Additional supports can be found through the help of child life specialists and psychologists, as they are specifically trained in child development and communication.

Ensure your children can identify a safe place to ask questions, even if it is not from either of their parents. Consider people in your child's life who you trust to make sure that the child has access to a safe place to talk and to ask questions. This could include someone on your treatment team, a teacher or counselor at school, someone from your religious community, or a close friend or family member. These supports should have accurate information about the patient's diagnosis and treatment. This will ensure that the child has access to solid and reliable information, in a supportive environment.

The initial discussion with your child will set the foundation for supporting them throughout the entirety of the treatment. Children will need to have a comfort and confidence that any questions that they have will be answered and that they will not be sheltered from information. As previously noted, any discussion will need to include age-appropriate information. Adolescents understand things that an elementary school-aged child may not. Gear any discussions with your children with this in mind.

Find SPOHNC at [www.spohnc.org](http://www.spohnc.org)



Inevitably, roles may change within the family after a diagnosis. One parent becomes the caregiver to the individual who is diagnosed. This affects the caregiving parent with added stresses, which can include maintaining a work schedule, accompanying the parent in treatment to medical appointments, assisting with medical care, paying bills, running the household, and managing the activities of any children at home. All of these additional tasks can impact the availability of the caregiving parent to their children. They may have less time and may be less emotionally available – which affects their relationships with the children.

Additionally, children will have changes in their roles and duties within the household. Disruptions in their routine can affect their sleep quality, and their participation in regular school activities. Some children also can become caregivers. They may take on some of the parents' responsibilities (both the caregiving parent and the parent who is being treated).

These increased responsibilities can affect the child's ability to interact with peers and their social development. It can also impact their education and ability to focus on age-appropriate events. With adolescents, we can see increased truancy rates with school. Some adolescents will take on additional work to help a financially stressed household. The impact all of this can have on childhood experiences is sometime significant.

Emotionally, we also see cancer affecting children and their lives. In younger children, we can see an emotional impact, including increased anger, anxiety, confusion, sadness, uncertainty, and fear, studies show. Some children can experience feelings of guilt about their parent's illness. The loss of hair and changes in the parent's appearance can affect the child's perception or comfort. Between 21-35% of adolescent children can experience post-traumatic stress symptoms (PTSS).

With a larger number of children and families impacted by cancer, awareness is increasing for how cancer affects the growth and development of our children. More study needs to occur, but we already understand that cancer disrupts a child's daily routine. If a parent is in treatment, the routine for the household is changed sometimes subtly and in other situations drastically. This is especially true if the treatment is in a different city or the parent is hospitalized.

This can affect the child's school routine, their connection with extracurricular activities, and their socialization. The more we can do as adults to lessen this impact on our children, the better. It is often better to keep the child in his or her own home environment when possible, especially if the parent in treatment has had to relocate to the treatment center.

There are many resources to help families dealing with a cancer diagnosis. A wide variety of national and local resources are available to keep patients and families informed about the diagnosis and treatments for many cancers. Your local treatment center and treatment team should be able to point you to resources available to you at national and local levels. Some of these services could include support groups, educational forums sponsored by organizations like SPOHNC, the American Cancer Society, Cancer Care, Cancer Support Community, Cancer.Net/ Talking with Children and more. These tools and resources exist to help families cope and adjust along their treatment journey.

Additionally, there are other resources, which can include organizations geared toward providing supports specific to children who are dealing with cancer for themselves, a parent, or sibling. In your community, your treatment team is likely aware of any resources like this that are available to you. These organizations can play an important role in helping children adjust and feel connected with others who are experiencing

## How Can SPOHNC Help You?

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or at [info@spohnc.org](mailto:info@spohnc.org)

a similar situation. These organizations can include summer camps, holiday activities, and support groups for children.

We need to ensure we are providing our children affected by cancer with greater supports. More study and focus should be made to adequately understand and develop resources that can assist patients and families with tools that can assure that we are not only treating the individual to rid them of their cancer, but also to provide the necessary supports to ensure that we are all emotionally cared for during the course of a treatment for cancer.

I encourage all treatment centers to enhance and invest in the services that they and their community provide to help patients and families as they seek treatment for cancer. As treatments evolve, we have a growing number

of children who experience cancer within their family. A growing body of knowledge will increase our ability to enhance support services for patients and families. This will improve quality of life for countless individuals. Support services will continue to be an important aspect of caring for everyone, and will affect lives moving forward.

Editor's Note: Michael Ellis, LMSW, has been part of the James P. Wilmot Cancer Institute and the Stem Cell Transplant and Cellular Therapy Program since 1997. He has a bachelor's in Social Work from Nazareth College, and a master's in Social Administration from Mandel School of Applied Social Science/ Case Western Reserve University.

“SPOHNC means so much to us.”

~ Deana

# April Awareness Approaching!

## *What Are You Doing to Raise Awareness in April?*

It's only February, but many people, and places, are already making plans to raise awareness of oral, head and neck cancer in April. Do you, or does your SPOHNC Chapter support group, have anything in mind? You could plan to host an oral cancer screening in your community, wear burgundy and ivory on Fridays, host a walk, run or other event to raise awareness. Whatever you do, take photos and share them with SPOHNC at [info@spohnc.org](mailto:info@spohnc.org).

You could also visit a venue near you that will be illuminated at night in SPOHNC's colors, to raise awareness. Our 2023 SPOHNC Illumination Family is already established and growing! If there's a place near you that will light the night in support of April Awareness, why not take a road trip and get some photos!

You can share them with SPOHNC, and we will include them (with photo credit to you, of course) in a future issue of **News from SPOHNC**.

To date, the following venues will be illuminated in burgundy (or red) and white to raise awareness:

- April 1 - The Helmsley Building at 230 Park Avenue – NYC
- April 2 - I-35 St. Anthony Falls Bridge – Minneapolis, MN
- April 8 - Sperry Tower – Eagan, MN
- April 10 - Wells Fargo Lights at 55. S. Tryon – Charlotte, NC
- April 11 - Indiana Power and Light – Indiana
- April 15 - The Gilbert Water Tower – Gilbert, AZ

Share your ideas and events with us, and we will continue to keep you updated with more 2023 SPOHNC Illumination Family members. Help us to raise awareness, because

Together, WE Heal!



# Sweets for Your Sweetie

## SPOHNC's RESOURCES



**Banana Puffs**  
— RECIPE —

**INGREDIENTS**

1 c. sugar	3 well beaten eggs
1 c. flour	¼ c. milk
1 tsp. baking powder	3 bananas

.....

Nutritional Information Per Servings:  
Calories 256(kcal), Total Fat 3(g), Saturated Fat 1(g), Cholesterol 81 (mg), Sodium 99(mg), Carbohydrate 55(g), Dietary Fiber 2(g), Protein 5(g).

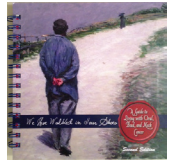
Mix eggs and sugar together. Add milk. Beat in flour and baking powder until smooth. Stir 3 thinly sliced bananas into the batter. Half fill buttered custard cups & steam or bake 1 hour. Yields 7 (1 cup) servings.

.....

Leslie S. - Illinois

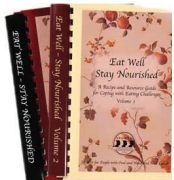
**We Have Walked In Your Shoes: A Guide to Living With Oral, Head and Neck Cancer**  
- by Nancy E. Leupold & James J. Sciubba, DMD, PhD

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## 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 a bill which if passed, would require insurers doing business in Massachusetts to cover medically related dental treatment.

**MOPSS needs your help!**

**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](mailto:THealy1019@gmail.com) or by phone at 781-686-3774 for details about the 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!!



# Survivor News

## NSVN Volunteer, Jeffery Shoop

Jeffery Shoop has been a member of our SPOHNC family since 2013. He has participated on several panels and committees, and is a member of our National Survivor Volunteer Network matching program. Jeff is also featured in our SPOHNC Survivor video which can now be viewed on our website at [spohnc.org](http://spohnc.org). His most beloved roles are that of husband, dad, and grandfather. Jeff is also a full time musician!

Currently, Jeff is also serving as a volunteer Advocate Liaison for the NRG Oncology Head and Neck Committee.



The most recent NRG Conference was held in Orlando in late January. At the conference, Jeff provided an update to the committee on the search for additional head and neck advocates. He also gained better information about new members who may be needed and the responsibilities they will need to fulfill.

Jeff has made it his own personal mission, through participation on this committee and through other panels and initiatives, to work on behalf of the head and neck cancer community on advancing treatments, funding and patient's quality of life during treatment and recovery. SPOHNC is honored to count Jeffery Shoop among our family of volunteers. Thank you for all you do Jeff. We are pleased to support your efforts, and we know that Together, WE Heal.

His responsibilities for this esteemed committee include attending meetings via zoom or in person at the bi-annual conferences; reviewing protocols and providing insight to new concepts/trials with the focus on the patient's behalf, including treatments and quality of life issues. In addition, he is also assembling a team to review consent forms to expand descriptions and definitions for patients. As someone who sought out his own information concerning clinical trials he could potentially participate in, Jeff knows first-hand the importance of this initiative.



Share yours  
with our readers!!!

Contact SPOHNC today at  
1-800-377-0928 or [info@spohnc.org](mailto:info@spohnc.org)  
to find out how.

## Chapter News

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

On December 17<sup>th</sup>, 2022, we had a very informative presentation from Soomin Richard Kim, DDS, MPH at our SPOHNC/UTSW Support Team Meeting.

Dr. Kim's presentation on xerostomia (dry mouth), hyperbaric oxygen treatments, osteonecrosis of the jaw and its causes and treatments, and the need for fluoride treatments for radiated survivors was very detailed



and informative. He took the time and patience to answer all of our questions in terms that were easy for us to understand.

Dr. Kim is a graduate of UCLA with degrees in Doctor of Dental Surgery and a Master's in Public Health and is associated with Dental Oncology Professionals, 6452 Broadway Blvd., Garland, Tx 75043  
[www.TexasDentalOncology.com](http://www.TexasDentalOncology.com)

Hybrid attendees included 10 survivors (including Zoom), 4 caregivers, and 3 healthcare professionals including a UTSW Social Worker. Two of the survivors were new to the group and promised to attend future Support Team Meetings. This was our first hybrid meeting with 3 survivors attending via Zoom.



# Head and Neck Cancer News

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

IQVIA™ ([www.iqvia.com](http://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.*



## Chapter News

### *SPOHNC Syosset Takes the Ice!*

January weather in New York brings cold, snow, and ice. None of those are fun to drive in, but Syosset Facilitator Frank Marcovitz and his adventurous spirit took the group out on the road again...this time to an indoor ice skating rink!

There were swizzles and crossovers and there was even some ice hockey skating going on as the brave ones who attended got out on the ice to skate. There were several of us who opted out, but we had fun watching everyone else, while being grateful for our safety!

The event was a family affair as several group attendees brought along their spouses and kids. We even had 2 new group attendees join us!



Following skate time, everyone gathered in a conference room for camaraderie, some board games for the kids, and tiramisu, which is always a favorite, provided by SPOHNC's Executive Director, Mary Ann Caputo. The event also turned into an impromptu support group meeting as stories were shared. The kindness and compassion of the group shined through as survivors upheld each other through some difficult moments.

We have a feeling this will be another SPOHNC Syosset, NY annual event, and we are so grateful to Frank for always thinking of ways to get together outside of the meetings. We look forward to his next idea!!

# February Champions of Hope

## Patrice and Lee Saurman

Our February Champions of Hope are a loving couple

Our February 2023 Champions of Hope are one amazing couple – and they have stuck together through thick and thin. Patrice and Lee Saurman began “their” cancer journey in 2007, when Patrice was first diagnosed, following a family vacation to the beach in Delaware. Patrice, being a nurse, was quite alarmed at the discovery of a lump on her neck, so she had it checked out right away. After a series of tests, she was told that she would need to see an oncology surgeon. Patrice shared her journey in the September 2017 issue of *News from SPOHNC*.



Patrice endured her cancer journey with the help of her husband, Lee, who was determined to help her every step of the way and he did everything he could to ensure that she would be comfortable and get through this journey as quickly and painlessly as possible. It was a role he did not expect, but it was a role he excelled at, and he still serves in that role today, as well

as being Co-Facilitator of the SPOHNC Penn Hershey, PA Chapter Support group. The group has been in existence since 2014 and they have become like family to each other. Patrice shared that she never would have imagined that one day she would be helping others by facilitating the support group. She is inspired by the group and the stories that are shared by others as they learn that they are stronger than they ever thought they could be.

Patrice and Lee have put together several special events with the group, one being their annual Garden Party, held at the beautiful home of one of their group attendees, which though on hold for a few years due to Covid, has returned this last year and we hope it will continue. The Chapter also participated in a day long Survivorship Celebration in April of 2021 in recognition of April Awareness.

At SPOHNC we honor our Champions of Hope for their kindness and compassion, their dedication and their unwavering support of others who are traveling their cancer journey. Patrice and Lee have been and remain a shining example of empathy and grace, and the kindness they share through their hearts is very much appreciated by patients and survivors and their loved ones along the cancer journey. They continue to inspire, share their own journey, and understand the needs of others.

For this, we recognize you, Patrice and Lee, as our February Champions of Hope. You are a loving couple, so it’s the perfect time to pay tribute to you, in February - the month of love! It is SPOHNC’s honor to count you among our family, where we know you will remain for many years to come. Thank you, from the bottom of our hearts, for all you do for those we both serve.

## We Treasure You!

### Walter Boehmler

On January 8th, a special birthday happened...and we want to celebrate it! Happy Birthday Walter Boehmler!

Walter has served as Treasurer of SPOHNC’s Board of Directors since the organization was founded more than 31 years ago. Walter works behind the scenes in a “job” that is crucial to every organization – and he does so with



a quiet joy and the utmost of professionalism. He is a very dedicated volunteer, and we value his expertise more than he knows. Walter is also one of the nicest, kindest people we have the pleasure of knowing.

Walter – we thank you from the bottom of our hearts for your tireless dedication to SPOHNC, and we hope you had an amazing birthday. Sending you our best wishes for many more!!





# 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.**



*Featured above is SPOHNC's Minneapolis, MN Chapter Support group.*

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

**SPOHNC**

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