

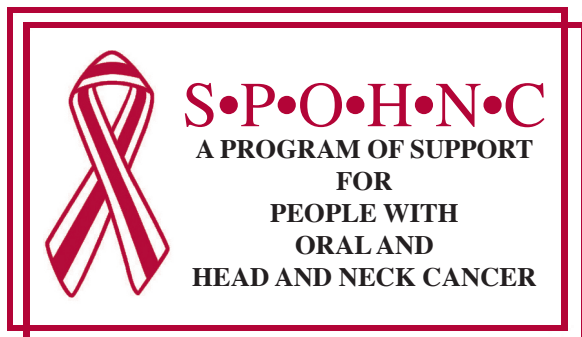
NEWS FROM S·P·O·H·N·C



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SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER, INC.

DECEMBER 2015



Holding On To Hope

Clare Butt, RN, MSN, AOCN, PhD(c)



For most people, hope is important throughout their lives' journeys. However, it can become even more so after receiving a cancer diagnosis. Cancer can change a person's view of life, and holding on to hope during these times of change can be a challenge. Surprisingly,

however, many people find their hope becomes stronger because of cancer.

So what is hope? A good description of hope can be found in Emily Dickinson's poem "Hope is the Thing with Feathers":

*Hope is the thing with feathers
That perches in the soul,
And sings the tune without the words,
And never stops at all.*

Emily Dickinson has captured the concept of hope by portraying it as a bird. This image fits well with what some survivors experience.

Capturing the idea of hope is difficult because it is alive and always changing, just as a bird is always on the move. However, we can follow the bird's action and flight and learn something about its nature. Dickinson's image of the bird, which "perches in the soul," embodies the need for this perching or presence of hope throughout all of life. While singing "the tune without the words," it "never stops at all."

It's easy to imagine the wings of a bird expanding to the left

and to the right, flapping in the air, and adjusting to the variations in the wind, thus producing flight. Applied to hope, the challenges of living with cancer can be said to provide the psychic energy that can expand a person's viewpoint, just as the wings of the bird expand to provide for flight. Indeed, an expanded view of the world can be seen from the perspective of flight. Many cancer survivors find new meaning through illness, redefining what is important to them.

Opposites may exist in a person's experiences during the journey through cancer. These may include sorrow and gratitude, inner strength and weakened abilities, withdrawing and embracing. Perseverance or persistent resolve may be the factor that kindles or gives energy to the unfolding that leads to uplifting possibilities. This uplifting, once again, brings to mind a bird in flight.

Emily Dickinson's poem goes on to say that hope is heard "sweetest in the gale." Hope's capacity to endure is great, since, as the poem states, "sore must be the storm that could abash the little bird that kept so many warm." Sometimes cancer survivors may struggle to bring life into balance. Some find that reflecting on their lives' journeys in order to bring it all together meaningfully is aided by the cancer experience. Hope is paramount as the past is revisited and renewed from the perspective of the present.

According to Emily Dickinson, hope can be found in every circumstance, even "in the chilliest land, and on the strangest sea." But how do you hold on to hope when times are tough? Each person must find his or her own ways to hold on to hope. See if any of these suggestions may work for you:

- Look for meaning in things that are larger than you. Maybe it's through nature, spirituality, or connectedness to a faith community.
- Anticipate survival. Many people have gone before you. Picture yourself among them – after treatment and doing well.
- Ask questions. You have a right to know about your care. Don't be afraid to ask the questions that can put your worries to rest.
- Seek affirming relationships. Family, friends, and pets can be a source of comfort to get you through hard times.

Turn to your inner resources. We all have more inside than we might imagine. Be gentle with yourself, and celebrate the little things in life that bring you joy.

Editors Note: Clare Butt has worked with persons experiencing cancer in various capacities for over 15 years. Her doctoral research involved the study of hope and quality of life in midlife cancer survivors. Currently Clare teaches nursing students at Holy Family University in Philadelphia.



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Chris Traxler

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Executive Director’s Message
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Thank You to SPOHNC’s Volunteers

“Healing is an intentional process by which a human being is motivated to accept their authentic life, through the exploration of internal thoughts, feelings, physical and spiritual connections – in a non-judgmental way and in a trusting environment. As a result of this acceptance, meaning and purpose transform suffering and the individuals perception is that life’s harmony and integrity are restored.”

~ Mark Gilbert, MD



SPOHNC’s Supportive Care programs include more than 125 chapters throughout the United States, as well as a National Survivor Volunteer Network with 200+ head and neck cancer survivors. Both of these programs offer hope and empowerment to each and every patient diagnosed with oral, head and neck cancer. Many patients and their caregivers benefit from the support given through these programs. Research has demonstrated that this type of supportive care has helped patients reach longer survival rates.

Each day, SPOHNC is very grateful for all of its survivor volunteers who help support head and neck cancer patients, caregivers and family members. It takes a very special individual to give back to society, make a difference and make sure another person’s journey with head and neck cancer can be overcome. No one knows the extent of the issues associated with head and neck cancer and its treatment better than one who has already gone through their own battle with this disease.

Each one of our volunteers helps to bring guidance and strength to all those affected by this disease. Their selflessness and knowledge helps to create an environment where patients and their families can feel secure and hopeful. They devote many hours to helping patients, and give their time to be there for those who will benefit from their experience, wisdom and expertise. In a situation that can often be traumatic and filled with worry, they provide a steady hand to ease anxiety and fears.

On behalf of SPOHNC, we would like to extend our deepest appreciation to the many healthcare professionals who facilitate chapters across the nation. They are a special group of individuals who understand from the point of diagnosis through treatment, a patient’s concerns and uncertainties. They offer each patient and their caregiver an appreciation to move forward and embrace each day.

SPOHNC is very grateful for the gift of ALL of our volunteers! They are the reason we are able to reach so many who are diagnosed with this disease, and offer support and encouragement throughout their journey with oral, head and neck cancer.

Each volunteer helps to transform many lives with harmony and integrity restored. Every concern, coping skill, and piece of encouragement given by our volunteers creates a bond that will never be forgotten. All SPOHNC volunteers are to be recognized for their humanity, strength and dedication. We ask that you join us in thanking them for all of their support and dedication.

Best wishes for a Very Happy and Healthy Holiday shared with family and friends.

With much gratitude, warmly,
Mary Ann

Mary Ann Caputo & the Staff at SPOHNC

HEAD AND NECK CANCER NEWS

Spying on Cellular Cross Talk

NIDCR scientists first to discover how embryonic salivary gland regulates its own innervation

April 30, 2015 - Many of the estimated 280,000 Americans who have survived oral cancer treatments contend with disabling dry mouth as a result of radiation therapy aimed at their mouth and throat. For these oral cancer survivors, the mouth is dry because radiation damaged the salivary glands. A dry mouth makes it challenging to talk and eat, and makes tooth decay, painful ulcers, and other problems in the mouth much more likely. For some oral cancer survivors, the salivary glands may never work well again.

So that someday doctors will be able to repair or regenerate salivary glands, Matrix and Morphogenesis Section Chief and Senior Investigator Matthew P. Hoffman, BDS, PhD, has been identifying the cells, signals, and other factors that are key for the gland's development. In a recent article in *Developmental Cell*, Hoffman and colleagues are the first to describe the cellular cross talk that promotes the innervation of the salivary gland. These findings are an important advance toward the goal of developing treatments that restore a cancer survivor's ability to make saliva.

Studying complex living tissues

For more than 65 years, scientists have been extracting salivary glands from mouse embryos and observing how they grow in living tissue culture. About 12 days after conception, a bud near the tongue forms in the embryo. This bud branches into three or four buds, and those buds continue branching until the embryonic gland looks like a cluster of grapes. Shortly after that, the solid cores hollow out so the gland can release saliva through ducts into the mouth.

About 40 years ago, it was discovered that while the branches and cavities of the gland are forming, nerves also develop and send out projections that weave around the gland to innervate it. By the 13th day after conception, researchers can separate the tiny embryonic nerves from the salivary gland (see image of red nerves overlaying a green salivary gland).

"As the salivary gland develops in the embryo, the different types of tissues are obviously communicating with each

other," said Hoffman. Using genetically modified mouse embryos to eavesdrop on the cross talk between the tissues, his team is identifying what drives the precise coordination.

Isolating progenitor cells

"For a cancer survivor who is unable to make much or any saliva, progenitor cells could be isolated from the patient's body and then transplanted inside the diseased gland along with the factors they need to enhance or restore the ability to make saliva," said Hoffman. Progenitor cells are precursor cells that have the potential to differentiate into many other cell types. Hoffman's team is targeting a number of cell types, including K5+ (keratin-5-positive) progenitor cells, for potential use in salivary gland regeneration and repair. In adults, K5+ cells can be isolated from a patient's skin, salivary gland, or other tissues.

In an embryo, the salivary gland needs a pool of K5+ cells in their precursor, undifferentiated state. If K5+ cells within the salivary gland all differentiate into other cells, the gland doesn't grow and develop properly. Five years ago, Hoffman's team published in *Science* their discovery that the nervous tissue maintains the K5+ cells within the gland in a precursor state. If the nerves are removed from an embryo, K5+ cells differentiate, the pool is depleted, and gland growth is impaired.

Discovering a novel interaction

"Many researchers are looking at stem cells or progenitor cells without taking into account nerve development and what may drive it," said Hoffman. And yet, for glands to work properly, nerves are as essential as the blood vessels that supply oxygen and nutrients.

The experiments described in the *Developmental Cell* article represent 6 years of work. One of the article's co-first authors, Wendy M. Knosp, PhD, was a postdoctoral fellow in Hoffman's lab at the time the most recent experiments were conducted. The project at NIDCR was a continuation of work she began as a postdoc at the University of California San Francisco (UCSF) in the lab of Gail R. Martin, PhD. Coincidentally, the

other co-first author, Sarah M. Knox, PhD, was a postdoctoral fellow in Hoffman's lab at the time of the research and is now a UCSF assistant professor and continues investigations of gland development in her newly established lab.

"We already knew that signals from the nerves keep K5+ cells as precursor cells," said Knosp, who is now a science policy analyst in NIDCR's Office of Science Policy and Analysis. "But what we were surprised to find is that K5+ cells are producing the signals required for the initiation of innervation." In other words, the cellular cross talk in an embryo is bidirectional. The nerve cells help the salivary gland to develop its branched architecture by maintaining the K5+ cells as precursor cells, and the K5+ cells within the salivary gland help the nerve cells survive and innervate the gland.

Using molecular techniques and living tissue cultures from genetically modified mouse embryos, Knosp was able to determine that the signals coming from the K5+ cells were proteins called Wnts. "When we treated the culture of fetal salivary glands with Wnt inhibitors, nerve development and branching were disrupted," said Knosp. "Normally, more than half of the nerve cells wrap around the gland's duct, but with the Wnt inhibitor, only about a quarter of the nerve cells were observed around the duct." The image on the right shows the dramatic difference between normal nerve cell growth (on the left) and its disruption after Wnt inhibition (on the right).

Knosp's experiments were confirmed using genetically modified mice that did not have nerves around the salivary gland. By studying these mice, she discovered that the gland did not produce the Wnt signals that drive innervation of the salivary gland. As a result, the gland did not form properly.

Knosp reasoned that what was true for salivary gland development would also be true for the growth of other glands. Because the key signals for innervation of the pancreas hadn't been discovered yet, Knosp repeated the experiments with embryonic pancreases from the same genetically modified mice. Her hypothesis was confirmed: Wnt signals also drive innervation of the pancreas.

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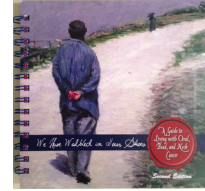
By showing that Wnt signals are necessary for nerve development, the study provides a new mechanism for the regulation of innervation. With the new information reported in *Developmental Cell*, researchers may be one step closer toward the goal of developing methods of regenerating or repairing complex glands.

- Knosp WM, Knox SM, Lombaert IMA, Haddox CL, Patel VN, and Hoffman MP. Submandibular parasympathetic gangliogenesis requires Sprouty-dependent Wnt signals from epithelial progenitors. *Development Cell* 2015; 32:667-677.
- Knox SM, Lombaert IM, Reed X, Vitale-Cross L, Gutkind JS, Hoffman MP. Parasympathetic innervation maintains epithelial progenitor cells during salivary organogenesis. *Science*. 2010;329(5999):1645-7. doi: 10.1126/science.1192046.

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"We Have Walked In Your Shoes" is a tremendous resource for OHNC patients."

~ Valerie T.

HEAD AND NECK CANCER NEWS

Patients Receiving Radiotherapy Have Increased Risk of Complications in Face Lift Procedures

Oct 22, 2015 - A retrospective review in *JAMA Facial Plastic Surgery* suggests that patients who have cervicofacial rhytidectomy (face lift) after radiotherapy are likely to have increased complication rates over patients who have not had radiotherapy.

The findings are important, because almost half of all patients with cancer will have some form of radiotherapy. Patients suffering from early-stage head and neck cancer are often candidates for radiotherapy, and the treatment can lead to scarring and radiation burns, among other side effects. Given that those scars are likely to be visible in many head and neck cancer patients, many seek cervicofacial rhytidectomy as part of post-radiotherapy treatment.

Radiation therapy can cause microvascular changes in the treatment area, which are permanent changes that can adversely impact the outcomes of facelift surgery. The amount of damage can depend on a number of factors, including the penetration level of the radiotherapy and the total dose of radiation.

The article was based on a retrospective review of the medical records of 16 patients who underwent cervicofacial rhytidectomy after completing radiotherapy for head and neck tumors and those of 16 age-matched control participants who did not undergo radiotherapy. Patients underwent treatment

from July 2006 through February 2014, with final follow-up in February 2014. Complications after surgery were reviewed and data for surgery type, technique, radiation dose and delivery method, and time to surgery after radiotherapy were analyzed.

The radiotherapy and control group patients were a mean of 62 years old. In the radiotherapy group, 8 of 16 were women; 14 of 16 were women in the control group. Two major complications--1 hematoma and 1 perioperative stroke--occurred in the 16 patients who composed the study cohort. In the control group, there was 1 case of transient facial nerve weakness and 1 case of cellulitis that was successfully treated with antibiotics.

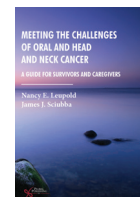
Two patients experienced wound dehiscence, and no incidents of motor or sensory nerve injury occurred. Subcutaneous face-lift (3 of 3 patients [100%] vs. 1 of 13 patients [8%] who underwent superficial musculoaponeurotic system and deep-plane face-lifts; $P = .02$) and the addition of chemotherapy (4 of 9 patients [44%] vs. 0 of 7 patients who did not receive chemotherapy; $P = .04$) were associated with increased complications. Notably, neither age nor time from completion of radiotherapy to facial surgery showed any correlation to complications.

According to the researchers, "The incidence of wound dehiscence is elevated in the population undergoing radiotherapy but can be managed conservatively in most cases. Patients who undergo radiotherapy must be counseled on the increased risk for complications before proceeding with cervicofacial rhytidectomy."

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Time for Sharing...The Journey is Life Changing

I am a tonsil cancer survivor. It is now almost 8 years since I finished my treatment at a Boston Hospital.

My treatment program was very intensive. I had radiation 5 days a week for 7 weeks. The doses were 5-7 times the normal dose. I also had chemo every Tuesday along with my radiation that day. They put in a G tube in October to help me eat. The problem however was that I was sick from the moment I woke up from the G tube surgery. I threw and threw from October 07 until the end of January 08 when they took the G tube out earlier than expected hoping that my stomach would finally calm down. During that time I could not eat, drink, walk or talk. I was in a wheelchair for months.

Fortunately I approached this journey with incredible support from my husband David, our son Daniel and my brother Gene. David handled everything from my diagnosis in September 07. He was a rock for Daniel and me. I simply could count on him to do it all and take care of me, which was no easy feat with a spreadsheet of medications that I kept throwing up and more appointments than any one person could possibly keep track of. I really don't know how he handled it, especially the constant worry. Our son Daniel continued with school and kept his grades up. This was an unbelievable achievement considering how much sickness he watched as my treatment continued. Daniel was always gentle and compassionate with me. He simply made my day each and every day! My brother Gene gave me the positive outlook that I needed going into the treatment. He told me that I had to think, "I will do it, I will beat it, I will hear good news every day." (no matter what little tiny thing it is I can find). He told me to only entertain positive thoughts. Gene gave me the mindset that I believe a person needs going in to face a treatment program. I often said it was like jumping off a high diving board. It was very scary.

My whole experience was compounded by the fact that we decided to go to Boston for my treatment. However, we live on Cape Cod. We commuted each day to Boston for 35 days, (at 5:15 A.M. to try and beat the traffic), which made my stomach upset even worse. I often say that if I was able to survive the treatment then I would probably survive the disease.

I know that I made the right decision to go with the team at the hospital we chose. They were experts on tonsil cancer and the needed treatment. They had a team approach and support system. They were so compassionate, gentle, reassuring and knowledgeable. My team became my best friends during that grueling experience. At one time I was hospitalized for 11 days because I was very sick with mucositis and nausea. I was pretty out of it at that point, but I do remember my doctor coming in to visit me every night before he went home, sometimes at 8 or 9 o'clock. He would sit there and listen and talk with my husband David and I. He would calm my fears. His gentleness and compassion is still very clear in my mind.

After treatment I had to find my life again. It was a very difficult time. Once again my brother Gene was there for me. His support and advice pointed me in the right direction. He told me simply to try going outside for a few minutes each day, even just out on the steps. Then after a few days, if I was feeling stronger, he suggested going a little further, such as walking around the yard. As I moved along that journey he told me to take it step by step. When the day was extra difficult he said to take it hour by hour if I needed to or even minute by minute. In the morning just get your feet on the floor. He suggested taking our dog out. She would enjoy it and he knew I would too. Go around the block, then down the street. Say hello to someone, give them a smile, chat for a moment, but most importantly, do a little something for them, a smile, a kind word, some encouragement. This helped me tremendously. It got me out and part of the world again. It made me feel good. It was amazingly helpful to try and make it a brighter day for someone else. It made me smile.

I also joined a local cancer support group. This was a tremendous help. I was able to tell my story and hear the stories of other survivors. We understood each other and we helped each other. There was a sense of solidarity. Years later I still attend this group; participating, gaining knowledge and validating others and their concerns.

About this time I created a pamphlet, "Patient to Patient, Survivor to Survivor."

It is brief, easy to understand and contains some tips and suggestions. It validates some questions, thoughts and concerns survivors might have. Hopefully it has been helpful to the many survivors who have read it.

Last year I developed late affects from my treatment. I was prescribed physical therapy for neck spasms. The therapy help somewhat, but mostly I needed to learn and implement correct posture and head position while completing daily tasks. This year I returned to P.T. when my neck spasms started once again. I was given more exercises to do on a daily basis which I do regularly. This gives me some relief if, ..., I "Mind my Ps and Qs."

My stamina has greatly improved and with that came an interest in trying some new activities that would help me physically and mentally. I started playing Mahjong, learning about Mindfulness and studying Tai Chi. Fortunately, I met a group of woman who were willing to teach me the rules and strategies of Mahjong. We play once a week and enjoy the social time together. Mindfulness was another interest. I read Herbert Benson's book, The Relaxation Response. Mindfulness helped me reduce stress by focusing on the present moment. For me, it is a work in progress. Tai Chi was a new challenge. I took classes and practiced and practiced and practiced. I was determined to learn all the 37 steps of Tai Chi. Now it is part of my weekly routine. It is restful, calming and improves my balance. During this time I was also able to gradually return to my exercise routine of walking on a treadmill 5 times a week. I have been able to increase my daily walking time from 25 minutes to 50 minutes. These self help strategies have empowered me. They make me feel as if I am doing something just for me. I am building strength and confidence throughout my journey.

I continue on my journey. Sometimes it is difficult. Mostly it is just plain wonderful. I have met many beautiful people that I would not have met otherwise. People have such goodness in them. I have experienced such compassion, love and support. Our family, our friends and our beliefs have walked beside us on this incredible journey. They were there for us when, quite honestly, we were all traumatized.

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It has been a humbling experience. I see life differently now. I would not have it any other way. Our lives continue to be graced with blessings we never expected when this journey began.

The years have passed and life has moved on. Almost 8 years. I worried I would make it, but I also believed "I would do it." And my belief was always the stronger of the two, guiding my way when I was most anxious.

It is my turn now to "Pay it Forward." I am grateful for my life and for each day. A window has opened for me; mentoring cancer survivors. Cancer survivors need someone who understands that moment of diagnosis, the difficulties of treatment and their ongoing journey. My first mentoring was with a woman by phone and email through SPOHNC, NY. We are still in touch with each other. I continued on with phone mentoring through a Boston hospital and in person mentoring with cancer survivors at a local hospital. I enjoy this work so very much. I always say, "It is good work to do."

A few years ago I started volunteering with the Mass Department of Public Health and the Comprehensive Cancer Prevention and Control Network as a survivor advocate. This work is very exciting. The cancer survivor landscape is changing. We are part

of the impetuous to empower survivors through wellness.

What more could ask for? Nothing more. If I am able to help even one survivor as they walk the path of their journey I have achieved my goal. The journey is life changing.

Addendum: My cancer was detected after a prolonged sore throat (I thought it was allergies). The doctors all acted quickly and followed the correct protocol. I was fortunate. Early detection is key. The public needs to be more aware of Head and Neck Cancers and their accompanying symptoms. It will save lives.

My son took this "Boardwalk" picture in January of 2008, about a month after I finished treatment. I call it, "My Journey." It captures the twists and turns of my path. I work diligently to empower myself and thereby continue on the boardwalk where I am safe and healthy.



~ Mary Lou Rossano-Collier
mlrcoceanview@yahoo.com



Watching for Winter

The trees are sticks against the sky.
The sky is gray, and so am I.
I watch the white that's wafting down
and printing patterns on the ground.
The ground is brown. It once was green.
Until that green again is seen
birds fly in lines across the gray
to seek a sun that's far away.
The warmth it brings is hiding now
behind the white that's drifting down
on bare brown ground and shivering trees—
Stay snow! And weave the robes you please.

Felicia Sanzari Chemesky

Appetizers are a great take-along when visiting guests during the holiday season. Try this recipe, from

Eat Well Stay Nourished A Recipe and Resource Guide For Coping With Eating Challenges Volume 2

Swedish Meatballs

1 ½ lb. ground beef
¾ c. dried breadcrumbs
1 egg
¼ c. onion, chopped
2 Tbsp. dried parsley
1 ¼ tsp. salt
¼ tsp. paprika
1/8 tsp. pepper
1 tsp Worcestershire sauce
½ c. milk
1 can bouillon or consommé
Cooking sherry



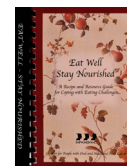
Saute chopped onions in a small amount of butter or margarine. Combine with all other ingredients and form into small meatballs. Simmer meatballs, covered, in a pan with a can of bouillon or consommé, seasoned with a touch of cooking sherry. Serves 6.

~ Nyra T., New York

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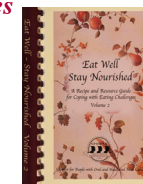
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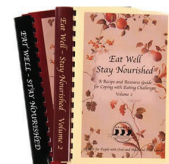


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HEAD AND NECK CANCER NEWS

Swallowing disorders may warrant routine esophagoscopy examination in patients with HNSCC

November 3, 2015 - No definite index of symptoms and signs indicated local recurrence or second primary malignancy in patients treated for head and neck squamous cell carcinoma, according to study results. However, the researchers strongly recommended routine transnasal esophagoscopy examination for these patients who experience swallowing disorders.

“In patients treated for head and neck squamous cell carcinoma (HNSCC), the incidences of local recurrence and secondary primary malignancy are relatively high,” Tseng-Cheng Chen, MD, of the department of otolaryngology at National Taiwan University Hospital and National Taiwan University College of Medicine in Taipei, and colleagues wrote. “In routine practice, a clinician inspects the development of local recurrence or secondary primary malignancy in patients treated for HNSCC by observing any symptoms and signs of swallowing disorders. However, the associated morbidities from previous treatment also can result in swallowing disorders. Therefore, swallowing disorders in patients treated for HNSCC are easily and frequently ignored in routine practice.”

Chen and colleagues sought to develop an index of signs and symptoms of swallowing disorders that could be used to predict local recurrence or second primary malignancy among previously treated patients with HNSCC. Further, they assessed the application of transnasal esophagoscopy in this patient population. The researchers identified patients treated for HNSCC with swallowing disorders who underwent transnasal esophagoscopy examinations between January 2010 and June 2014. They pathologically diagnosed local recurrence and second primary malignancies.

The study included data from 136 patients (mean age, 59 ± 12 years; 90% men). Seventy-seven percent of patients had advanced-stage (stage III or stage IV) HNSCC. The researchers confirmed local recurrence in 32 patients and second primary malignancy in 14 patients, representing approximately 33% of the patient population.

Simultaneous local recurrence and second primary malignancy occurred in one patient. Among patients with second primary malignancy, 10 patients had tumors in the head and neck region and four patients had tumors in the esophagus.

No significant differences in age, sex, primary tumor location, stage and previous treatment modality occurred among patients with or without local recurrence or second primary malignancy. The positive predictive values for local recurrence or second primary malignancy were 38.24% for patients with odynophagia, 36.36% for easy choking, 30.99% for dysphagia, 28% for prolonged tube feeding and 25% for lumping throat.

Dysphagia served as the most frequent swallowing disorder among patients (n = 71; 52%). Other swallowing disorders included odynophagia (n = 34; 25%), prolonged tube feeding (n = 25; 18%) and easy choking (n = 22; 16%).

No significant difference existed between patients with or without local recurrence or second primary malignancy regarding swallowing disorders. The researchers could not determine an obvious index of symptoms and signs of swallowing disorders that significantly indicated local recurrence or second primary malignancy.

Further, the researchers did not observe any major complications after transnasal esophagoscopy, and they noted the procedure is the most effective method for inspecting for local recurrence or second primary malignancies.

The researchers acknowledged limitations of their study, including the study population’s sole inclusion of patients with swallowing disorders and the relatively small patient population.

“Direct inspection for local recurrence or second primary malignancy by using transnasal esophagoscopy is essential,” Chen and colleagues wrote. “The necessity and benefits of using transnasal esophagoscopy are crucial for patients treated for HNSCC, particularly for those with swallowing disorders.” – by Cameron Kelsall

Disclosure: The National Science Council of the Republic of China funded this study. HemOnc Today was unable to obtain a list of the researchers’ relevant financial disclosures at time of reporting.



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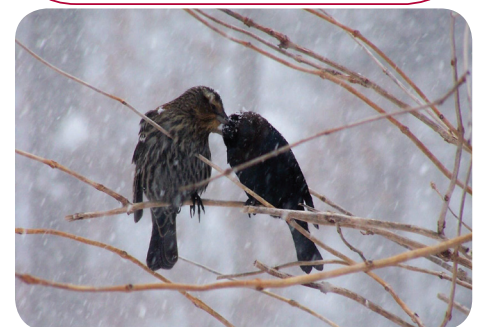


Photo courtesy of PJ Jordan

2015 Awareness Event Highlights

On Saturday, April 25th, the Grand Haven Village Community Center was abuzz with activity as the 3rd Annual SPOHNC, Palm Coast, FL Move to Music Exercise



Fundraiser began. The event is organized each year by SPOHNC Chapter Facilitators Amy and survivor Lewis Beilman.

Event supporters began the morning by visiting some of the information booths, gathering cancer support information, and some giveaways offered by local resources as well - then more than 70 brave individuals joined in to do the Move to Music aerobics class. The MTM CD opened with *Staying Alive* by the Bee Gees and



cooled down with Tim McGraw's *Live Like You Were Dying*. Participants included several oral cancer survivors and six survivors of other cancers.



Backpack bags containing specially made SPOHNC cookies along with



oral cancer information and hospital giveaways were given to all the registrants. As usual, the class was upbeat and energizing. Everyone had a fabulous, fun time!

After the class, bagels, cookies and coffee were served while the raffle

drawing of over 1,500 sold tickets took place. Many local businesses participated with gift certificates. There were some great gifts offered in the raffle at MTM 2015!

This year's fundraiser beat all expectations, both financially and in the fun category. The spirit and enthusiasm within the group.....the genuine concern for each other.....the pride of being grateful for each day.....everything was perfect.

Amy and Lewis couldn't have been more grateful for all of the support shown that day. They were especially thrilled to be able to help SPOHNC, who helped them so much when they went through their oral cancer journey.



The Kansas City, KS Taste Event was a great success once again! This year's guests in attendance were treated to a wide array



of delicious and delectable treats donated by local establishments, and the crowd was very attentive as some amazing speakers took the microphone.



Survivor, Holly Blythe, was the first to speak. Holding everyone's attention, you could hear a pin drop, as Holly shared his

experience throughout his cancer treatment. It was surely not an easy journey, and we thank you Holly, for sharing your story.

Jessica Barton, Speech Therapist, also spoke, updating the crowd about new developments in speech therapy. Survivor, Barbara Burks spoke next, sharing her experience with speech therapy and how it benefited her. Speech therapy enabled Barbara to change



her life, when she was initially told that she would not be able to eat beyond using a feeding tube.

Speech Therapy helped her to have her feeding tube removed and she was able to start eating again. Of course, she was very pleased with the outcome!

Entertainment for the day was provided once again by a local DJ, who donates his services each year to bring some terrific tunes to go along with the celebration.

Kudos to the Kansas City, KS SPOHNC Chapter attendees, and Facilitators Dorothy Austin, RN and Jane Myer, LCSW for another stellar celebration. We hear plans are already in the works for next year's big day!



continued on page 9

Connect with SPOHNC's "group" on Facebook

continued from page 8



On Wednesday, April 8th, 2015, EvergreenHealth and Cancer Lifeline, and the SPOHNC Seattle, WA Chapter hosted the 6th Annual Nibbles & Noshes; a free social and educational event for patients, survivors and caregivers living with Oral, Head and Neck Cancer. Guests at this reservation only event were treated to the taste of small Nibbles and Noshes, and enjoyed a special music performance. A very special evening was enhanced by guest and humorist speaker, Terri Tate, who presented "A Crooked Smile – An Oral Retrospective." Terri took guests along on her harrowing, yet often hilarious, journey, from looking good on the outside while a toxic inner critic lurked within; to wearing her woundedness for all to see and enjoying a hard-won inner peace. Terri Tate RN, MS is a speaker, storyteller

and consultant whose life and voice were threatened by two bouts of oral cancer from which she had a 2% chance of survival, but her sense of humor was never in danger. Terri's hilarious solo show, Shopping as a Spiritual Path, chronicles life's challenges and triumphs. Audiences across the country are moved to laughter, tears and standing ovations by her powerful performances.

Editors Note: These three events are just a small sampling of how awareness of oral, head and neck cancer was promoted this year. There were many free oral cancer screenings, awareness and educational tables and displays at health fairs as well. SPOHNC is committed to sharing your Chapter News and Awareness Events with our audience of those who have been affected by the diagnosis and treatment of oral, head and neck cancer. Please keep in touch and let us know. Thank you for your help in promoting awareness of oral, head and neck cancer. SPOHNC is grateful to our Chapter Facilitators and Co-Facilitators, and our Chapter group attendees and other volunteers, for all of your hard work and dedication.

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Chapter News - Tips From the Pro's

SPOHNC Chapters continue to support one another throughout the holiday season and beyond. Our lives can be so busy at this time of year, and if you've just completed your treatment, you must take time to care for YOU!

Many thanks to the attendees of the Palm Coast, FL SPOHNC Chapter, who recently put together some tips, and notes, to help you through the toughest part of your journey. They continue to inspire the people that know them and they continue to become family to the new people that find their way to this very special SPOHNC Chapter Support Group.

Please note that SPOHNC does not endorse any treatments or products here. Consult with your physician before using any of the suggestions presented.

From the group... Welcome to the New Normal! Congratulations on having marched through a very tough journey. Treatment for head neck cancer is one of the hardest to endure. You are now officially a survivor. Whether or not you received surgery, chemo, radiation or a combo of any of the three...

the end of the treatment cycle means the beginning of the next chapter: the healing period.

Unfortunately, the first few weeks after treatment can be challenging. Patients are left with issues that are not always discussed beforehand. Unless you have a large support group of head neck survivors to network with, you might feel alone and worried about some of the side effects that are now part of your life. This information should help you feel like you are not alone.

Everyone heals differently and at a different pace. No crystal ball will be able to predict how you will heal. The good news is you will eventually feel better and with time, many of these issues will go away or diminish. Hopefully these suggestions will make a difference to you in your recovery period. Here are just a few...

TROUBLE SLEEPING

Sleep Medication - OTC
Take Intermittent Naps
Anxiety Med. (Ativan) – Prescription
Sleep In Recliner

Use Wedge Pillow
Pain Med (Lortab) – Prescription
Pain Med (Fentanyl Patch) – Prescription
Wedge Pillow
Cool Mist Humidifier
Nose Balloon to Improve Breathing
Spray Mister
Recliner Chair
Red Bucket to Spit In
Plenty of Paper Towels



Stop & Sit A While

I awoke on Saturday, November 7, 2015 and looked outside, hoping to see a glorious, sunny day and said "OH NO!"... another dreary, overcast, rainy day. My thoughts went back to another dreary, overcast, rainy Saturday morning on April 25, 2015, the day that we had planned for the first 'Rick Agee Memorial Skate/Run-4-SPOHNC' event. Just like the Saturday morning in April, I went to my 'Ace in the Hole' and said, "Rick, I know you are listening. Please



see what you can do to help us out with turning this dreary, overcast, rainy day into one of sunshine and gentle breezes. I am sure you know the PERSON to ask!"

Low and behold, the dreary November

Saturday, just like the dreary April Saturday turned from dreary to sunshine and gentle breezes.... just what we needed for the dedication ceremony at Richardson Heights Park in Richardson, Texas for the dedication of a tree planted and a park bench installed in the memory of our friend Rick Agee who was taken from us on February 19th, 2015 by Oral Cancer.



The tree, planted in Rick's honor, was provided and paid for by personal funds of the 'SPOHNC Chicks' (A term he used for Nancy, Mary Ann, Chris and Lisa in New York) and the park bench was provided to honor Rick, by funds from the 'Rick Agee Memorial Skate/Run-4-SPOHNC' event. The Richardson Park Department provided the installation of the tree and the park bench in the Richardson Heights City Park. The bench is located in a place that a person sitting on Rick's park bench has a view of Rick's tree in the park. This is the park where Rick and his wife, Lynn, walked and spent



many hours during his cancer journey.

The dedication event was attended by over 50 of Rick's family, friends and fellow Oral Cancer friends. Rick's park bench and tree were decorated with balloons, plus the tree had a wind chime hanging in it. The wind chime had been dedicated in Rick's honor and will permanently hang in a tree in the yard of



his Father and Mother, who live not far from the park. The event included sandwiches, chips, soft drinks, water, coffee and desserts, provided by the Rick's family, for all of the attendees.

Jack Hess, the husband and caregiver for Pam Hess, Survivor, captured all of the festivities in pictures and are featured here. Pam's cancer journey was featured in the November SPOHNC Newsletter. Pam was an inspiration to Rick as she is to many of the



Dallas/Fort Worth OHNC Survivors.

The day concluded with the presentation of a check by myself and Dan Stack, facilitator of the Irving, Texas Chapter, to Lynn Agee to be forwarded to SPOHNC for the Rick Agee Memorial Fund. The check for \$5,000.00 came from proceeds of the 'Rick Agee Memorial Skate/Run-4-SPOHNC' event for 2015.



It turned out to be an awesome day for a memorial for a man who gave so much of himself to others. We miss you, Rick!

~ Jack Mitchell, Survivor, 2001

In 2015, thanks to your very generous support, SPOHNC has been able to:

- Help more than 1,000 patient callers and their families to find the resources and information they so desperately need.
- Match more than 300 newly diagnosed patients and caregivers with a caring and compassionate volunteer from our National Survivor Volunteer Network.
- Open 10 new SPOHNC Chapters, assisting newly diagnosed patients, caregivers and their families along their cancer journey.
- Provide information and support to our 128 existing SPOHNC Chapters.
- Provide print resources to more than 15,000 newly diagnosed patients, survivors and caregivers.
- Publish our 8 annual issues of "News from SPOHNC" providing knowledge and expertise shared by medical professionals, inspiring Sharing Stories written by survivors and support to those who have been affected by the diagnosis and treatment of oral, head and neck cancer.

Thank you for helping SPOHNC to provide critical programs and services of support for more than 20 years. We couldn't do it without you.

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