NEWS FROM
S•P•O•H•N•C

VOL. 28 NO. 4 SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER, INC. DECEMBER 2018

S•P•O•H•N•C
A PROGRAM OF SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER

My Therapist Has Four Legs
Animal-Assisted Therapy

David E. Williams, MD

Researchers have been studying the impact of dogs on humans for over thirty years. They have looked at their roles as pets, in therapy work for health and wellness, for grief recovery, on inter-human relationships, for reducing pain and anxiety, and increasing productivity at work. Pet therapy is a broad term that includes animal-assisted therapy and other animal-assisted activities. Animal-assisted therapy (AAT) is a growing field that uses dogs or other animals to help people recover from or better cope with health problems, such as heart disease, mental health disorders and cancer.

A therapy animal team consists of a person called a handler and a therapy animal, both trained to provide healing interactions with patients. The objective of AAT is to help an individual, typically a patient in a hospital or care facility, overcome or recover from a mental disorder or health problem.

Dogs and cats are the most common animals used in pet therapy, however, horses, guinea pigs, rabbits, pigs, birds and other animals that meet strict criteria can also be used. The type of animal chosen depends on the therapeutic goals of the individual's treatment plan, what pet the individual prefers, and what their medical care team believes is the best fit.

Therapy dogs have had a significant impact on cancer therapy. According to a study conducted by researchers at Mount Sinai Beth Israel, patients receiving intensive radiation therapy for gastrointestinal and head and neck cancers experienced increases in emotional well-being and quality of life when they received visits from a certified therapy dog during the course of their treatment.

A Mayo clinic oncologist, Dr. Edward Creagan, has been quoted as saying "A pet is a medication without side effects that has so many benefits. I can't always explain it myself, but for years now I've seen how instances of having a pet are like an effective drug - it really does help people."

The anecdotal evidence of therapy dogs impact on cancer patients is now starting to be supported by rigorous study. The National Institutes of Health (NIH) has started an interventional clinical trial to assess the effectiveness of the NIH Animal-Assisted Therapy Program on distress in oncology patients treated for pain. The results of this trial should be released in the next few years.

In 2009 Coakley and Mahoney proved in a Massachusetts General Hospital Study - "Health Benefits after a Ten Minute Therapy Dog Visit " that a ten minute therapy dog visit lead to a 3% slower breathing rate, a 22% drop in pain severity, a 19% boost in energy, a 48% decrease in depression, a 64% drop in feelings of anger and a 39% decrease in fatigue.

As an emergency medicine physician, a member of Pet Partners and part of an animal-assisted therapy team myself, I've witnessed firsthand the power of the human animal bond. My daughter and I and our dogs Gia, a Bouvier des Flandres, and later Buttercup, a golden doodle, have visited the physically and mentally disabled at the Misericordia nursing home in Chicago and also cancer patients at St. Mary's Hospital in Chicago.

What has really inspired us about therapy dog work is how the animals treat each patient with the same level of affection and love unconditionally, regardless of their mental or physical disability or affliction. Many times illness or disability robs people of their self-image and self-worth. But the unconditional attention of a dog, non-discriminatory from their condition, can do more to empower and to help heal them emotionally and psychologically than any medication or pill. The evidence is now clear: Dogs do make a difference.

Editor's Note: After completing undergraduate work at Princeton, Dr. Williams earned his MD from Harvard and his MBA from Northwestern. He has served as Medical Director and Staff Physician at several prestigious medical facilities as well as Associate Chairman at the Mt. Sinai Hospital, Department of Emergency Medicine. Dr. Williams joined as Chief Medical Officer for Pet Partners in late 2015. As healthcare delivery increasingly recognizes the benefits of therapy animals, Dr. Williams will help Pet Partners to have a voice that represents the science, as well as the organization.

Today, Dr. Williams works with the Ocala Regional Medical Center, a level 2 Trauma Center close to Orlando, Florida and with Sheridan Healthcare as part of their Emergency Medicine

THERAPY continued on page 2

Make a Difference. Give a Gift Today.

S·P·O·H·N·C
Support for People with
Oral and Head and Neck Cancer
1991

News From SPOHNC is a publication of
Support for People with Oral and Head and Neck Cancer, Inc.

IN THIS ISSUE

THERAPY continued from page 1

Travel Team. As Chief Medical Officer, Dr. Williams is the chief spokesperson for Pet Partners articulating the human health benefits of the HAB and HAI. He keeps abreast of research in the field, creating position statements and interpreting the research for staff and volunteer leadership for program delivery and mission fulfillment. This is a key position as a Pet Partners initiated coalition develops the evidence-based public health message that companion animals are good for health.

Art Therapy

Ashley Jones, MA

I often find, Art Therapy is a new term to many of the people that I meet. As a result, there are a lot of question around what exactly art therapy is or does. Regularly, individuals assume that since "art" is in the title that it must only be for children or that I'm a recreational "craft lady." I have even had a few individuals think that art therapy is a new term for art restoration. I hope that as you continue to read, you will have a better understanding of what art therapy is and how it can be a great resource for a variety of individuals.

Art Therapy is a mental health profession that integrates the creative properties of art making into the therapeutic process, with the goal of guiding the participant to make healthy and positive change. There is no limit on a participant's age or diagnoses. Like many other mental health professions, Art Therapists tend to specialize in different areas of treatment or populations. In order to become an Art Therapist, you must have a master's degree in Art Therapy or counseling with a specialization in Art Therapy, and hold one of our national credentials. Those credentials are a Registered Art Therapist (ATR) or Board Certified Art Therapist (ATR-BC).

So what does Art Therapy look like? Art Therapy can look like a variety of things, from working in an Open Art Studio, like the one we have at Baylor University Medical Center, to a one-on-one session in an office space. When working with an Art Therapist, your goals can be anything from psychological, to physical, to spiritual depending on what is appropriate for the setting and the needs of the client. During sessions a variety of materials may be introduced from painting, to clay, to sewing, or found objects. The options are limitless.

I regularly hear, "Well, I don't have any artistic talent," or "I can't even draw a stick figure." A great part of art therapy is that you do not need to have any artistic ability to gain something from the creative experience. Many times, the process of making the art itself if more satisfying and enlightening than the end result. All that is needed is a willingness to try. The Art Therapist is trained to have a variety of art making skills and is there to help you through that process as needed. One distinction that I continually make in my own practice is that I am not an art educator. I am happy to give tips and tricks, and be present during the art making process as a guide, but my goal is not for my clients to become the next Leonardo Da Vinci.

When it comes to Art Therapy in the medical setting there are a lot of factors at play. Some of those factors include limitations

THERAPY continued on page 3

THERAPY continued from page 2

of space, the physical and mental readiness of the patient, schedules, etc. For example, those with current or past oral, head and neck cancer, the way of interacting with others is often never the same for a variety of reasons, which makes art and art making an even more powerful tool for these individuals. Not only can art be used to help a person be reflective and process how they themselves are feeling, but it can also be used to communicate to others without the necessity of words. If you think about it artists have been communicating, reflecting, and recording not only their personal feelings, but those of societies, for hundreds of years.

Art making can also be empowering. Many times adults don't allow themselves to be creative for one reason or another, or think that art is only for children. In fact, art is for everyone, and the best part is there is no "right" or "wrong" way to make art. Once an individual allows themselves the freedom to try, they are often surprised with the results they see and feel. The art making process can often reveal a talent or skill that the participant may have never known they were capable of had they not given themselves the opportunity.

A common theme or topic that I encounter with individuals that have oral, head and neck cancer is food. Sometimes it is a temporary frustration as a person goes through the healing process. For others, the relationship to this staple in our lives is never the same. This topic can be particularly difficult when it comes to social gatherings and the holidays, as most of these events are encompassed with food. As a result, for individuals that are limited to what they can eat, or are strictly nourishing their bodies through a feeding tube, these every day occurrences can provoke a variety of feelings including anxiety, isolation, frustration, embarrassment, etc. By working with an Art Therapist, an individual struggling with these issues may find a healthy release from these negative feelings, while also figuring out what coping strategies work best for them. This may also lead to the individual learning different ways to communicate what their new normal is to friends and family, as well as what support will be needed in the future.

Keep in mind, though, that the few examples I have given you here are only the tip of the iceberg that is Art Therapy and the benefits it can have. To learn more about Art Therapy, or to find an Art Therapist in your area, please visit the American Art Therapy Association website at www.arttherapy.org.

Editors Note: The SPOHNC Dallas, TX Support Group was fortunate to have Ashley do a session in Art Therapy at a recent support group meeting. Thank you to Chaplain Alan Wright for putting SPOHNC in touch with Ashley!

Ashley Jones is a Board Certified-Art Therapist, and LPC-Intern (Supervised by Elizabeth Stewardson, MA, LPC-S, MT-BC). She currently works at Baylor University Medical Center at Dallas. As a member of the Arts in Medicine team, Ashley provides Art Therapy opportunities tailored to patient's needs. The goal of her work is to engage patients in the creative process as an antidote to the pain, anxiety, depression, etc. often associated with a hospital stay or diagnosis of a serious illness. . Her work also includes staff education and development of the Arts in Medicine programs, with a primary focus in art. She runs an open art studio five days a week for patients, caregivers, families, and staff members. Ashley completed a BA in art and psychology at Austin College, and earned a MS degree in Art Therapy at Florida State University.

5 Ways to Keep the Holidays Happy When Dealing With Cancer

Christina Bach, MSW, LCSW, OSW-C

The holiday season can be stressful enough, but when you or someone you love has cancer, the season can be overwhelming. Use these five tips to reduce stress and keep the 'happy' in happy holidays!

1. PRIORITIZE! Decide which traditions are most important to you and ditch the rest this year. Focus on quality, not quantity. Delay some visits until after the new year.

2. Communicate – Communicate your wishes clearly with loved ones. What do you need to make things easier? What gifts would you appreciate most? What do you want to do? Set limits and remember, it is okay to say "no"!

3. Care for yourself (Caregivers, this means you too!) Take time for yourself, ask for help and know when to say no. Acknowledge that dealing with cancer may impact your holiday traditions. What can you control and what should you just let go of? Get enough rest and try to maintain a healthy diet to help boost your energy level.

4. Validate your feelings - Think about your feelings – how do you feel about the holidays and why do you feel this way? How does that influence your actions? Understanding these feelings can help you make decisions that support YOU. It is okay to not celebrate and your loved ones will (or should) understand.

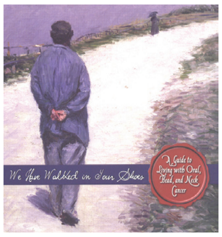
5. Develop your elevator speech - Think of some responses to the questions you often get in social situations. Have responses that deflect from the cancer – for example, "I am feeling good, how is school going for your son?" or "I had a rough month, but I'm doing a little better. How is your mom doing with her recovery? People feel obligated to ask or fear they appear insensitive, but if you redirect them, they are usually happy to talk about something else. If you think about responses ahead of time, you will find those interactions a little less uncomfortable.

Republished with permission from OncoLink, www.oncolink.org. Original publication date 12.10.13

Make a Difference. Give a Gift Today.

“May the Lights of Hanukah usher in a better world for all humankind”

We Have Walked In Your Shoes: A Guide to Living With Oral, Head and Neck Cancer Second Edition



by Nancy E. Leupold
& James J. Sciubba, DMD, PhD

$14.95 includes shipping and handling.

Bulk order pricing
25+ books $13.50/book
50+ books $12.50/book including shipping & handling.

For bulk orders
please call 1-800-377-0928
or email us at info@spohnc.org

Happy Holidays From SPOHNC!

Together We Heal…Thank you to all of SPOHNC’s volunteers who provide much needed kindness and care to those who are diagnosed with oral, head and neck cancer. We are forever grateful to you. SPOHNC values all of the support received through our Facilitators and Co-Facilitators and mentors of our National Survivor Volunteer Network. Your stories of help and guidance encourage others to go forward and become empowered, strong and above all a survivor!

Volunteers are a very special breed. They’re not afraid to step in when they see the need. They’re always willing to lend a hand…To lift someone up who’s sinking in quicksand. They always have something encouraging to say and they manage to say it in the kindest way. They share their skills, talents and time, and they seek nothing in return.

To be a volunteer, it takes...

Generosity, a willingness to give your time to others.

Understanding, because their lives might be very different from your own.

Empathy, an ability to put yourself in someone else’s shoes and feel what they must feel...

Compassion, to truly care about making someone else’s life better.

Patience, because the process doesn’t always go as smoothly as it might.

Dedication, to stick with the project and see it through...

So the next time you meet with a volunteer, shake their hands, and let them know you’re happy they’re there for you.

The gift of time is priceless – SPOHNC thanks each and every one of you for making a difference today and tomorrow. Your undivided attention and love will always remain with those you helped get through one of the most difficult times in their lives. Your unselfishness and commitment will stand the test of time.

Thank you to all of SPOHNC’s volunteers who sacrifice part of their lives to become a friend to those in need.

All of us here at SPOHNC wish you a beautiful holiday filled with love, light, happiness, hope, health and peace, always!

Fondly,

Mary Ann Caputo

Mary Ann Caputo,
Executive Director

Photo credit PJ Jordan,
SPOHNC NSVN Caregiver Volunteer

“At Christmas, all roads lead home.”
~ Marjorie Holmes

IN MEMORIAM

Richard Broome

Shared by Lee Saurman - Co- Facilitator - Penn State Hershey, PA SPOHNC Chapter

When Patrice and I held the first SPOHNC meeting at Penn State Hershey, a man entered the room who we had never seen before. With a bit of difficulty, he introduced himself as Richard. Seeing that he was a laryngectomy patient, we knew he was in the right place. He was very quiet at first, hanging back some, listening to everyone sharing and learning, but soon he started feeling at home, (especially when a few of us guys started joking around him a bit). But you could see that he knew he fit in and soon, he began to make his presence known. He was a joker, always making us laugh. Occasionally, he would write a comment for one of us to read out loud to the group, and we would read it and laugh but would have to tell him, "I can't read this out loud, Richard!" because it would be a little naughty or inappropriate. Other times, he would "act out" what he wanted to say, always with great humor.

He continued to show up for the meetings. Every. Single. One. In time we learned that his treatment for oral, head and neck cancer included a very rigorous, risky surgery reconstructing his throat that had taken many hours. The possibility of him surviving was slim and yet he did. He was a fighter.

He shared with us that he lived alone, with a good bit of property to take care of. He still chopped fire wood, harvested fruits and vegetables, and drove himself wherever he needed to go. Richard showed us an issue of a Lancaster, PA magazine that had featured some of his beautiful cabinetry work and his wood sculptures he had done for people. You see, he had been a real craftsman until his cancer treatments had left him unable to continue producing such fine work. I know it weighed heavily on his spirit that he couldn't work any more.

On two different occasions, when Patrice needed help, he went all around the Med Center distributing and posting flyers for the group. Since he was there often enough for his own care, he knew all the places where head and neck cancer patients would be sure to see them, and he wanted to contribute. He loved to "razz" the nurses, who nicknamed him "Trouble." But they were always glad to see him when he walked in the door.

Then one day, he gave us the dreadful news that he now had cancer in his lung. Some of the tumors wouldn't respond to treatment, and others did. But they wouldn't go away. And he still came to every meeting except for one, and continued to do so until he just got too weak or was in too much pain.

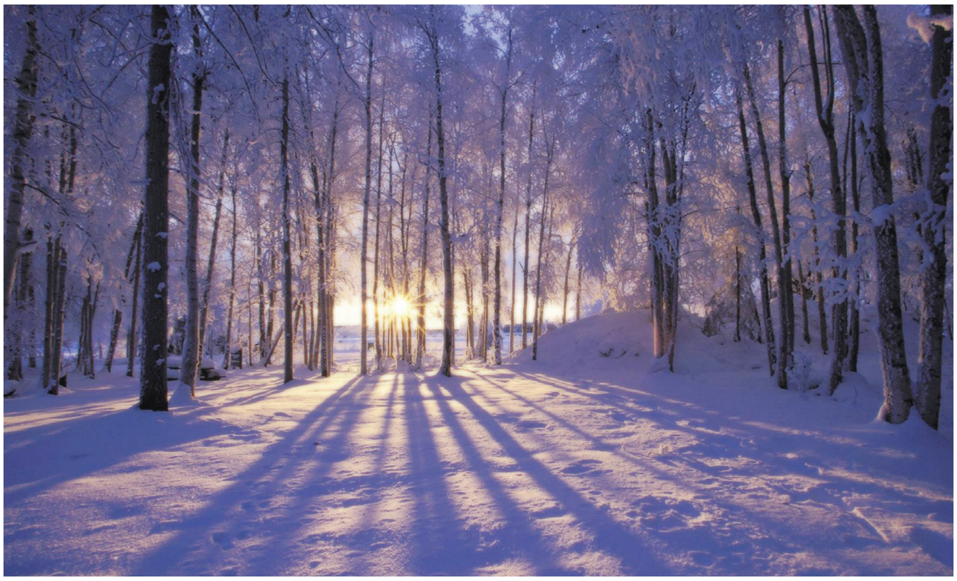
His cancer continued to spread to other parts of his body, his hip in particular, leaving him unable to move about like he always had. He spent many of his days in pain. We offered to help him so many times, but he was extremely independent (and extremely stubborn!) and refused any help from us. He would do things on his own terms, no matter what it took. And that's what he said kept him going — to be able to do something … anything for himself.

But he so appreciated all of the cards and notes of encouragement he received from the group. He said it made him realize that there are good people in this world who do care, and he was very touched by that.

Sadly, we won't be seeing our friend "Trouble" anymore. He will be dearly missed.

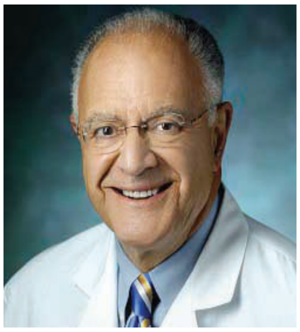
On Sunday, October 28th, Richard Broome's battle with cancer came to an end. His pain is gone, and I personally believe he is now of whole body. But what a fighter he had been!

Richard was such a big part of our group. He always will be.



Shop with Amazon Smile to Support SPOHNC

SPOHNC IS CELEBRATING YOU!



Twenty nine years ago, James J. Sciubba, MD, DDS was instrumental in supporting SPOHNC's Founder, Nancy Leupold, in the start-up of SPOHNC. Through the years, Dr. Sciubba has continued to be a staunch advocate for the organization, and for those who have been affected by the diagnosis and treatment of oral, head and neck cancer. He now serves as our Board President, and provides expert advice and counsel to keep SPOHNC working toward our mission. As a highly respected healthcare professional, Dr. Sciubba has written many articles, participated on many professional conference panels and appeared as an expert speaker in many videos. There's even one on SPOHNC's brand new website!

As you can imagine, it's hard for such a busy man to take time out to relax and celebrate, but we hope Dr. Sciubba did just that for his birthday, which he celebrated on December 12th.

Maybe Dr. Sciubba was out taking some of his very well-known photographs on his birthday or vacationing somewhere special, or perhaps he was at home enjoying time with family and friends. Wherever you were, we wish you all the best for your birthday and the coming year. May you enjoy peace, good health and prosperity all year long.

Happy Birthday, Dr. Sciubba! SPOHNC Celebrates You!

SPOHNC wants to share your news!

Send us your birthdays, good news, Chapter News and Sharing Stories

Inspire Someone Today

Contact SPOHNC at 1-800-377-0928 or e-mail us at info@spohnc.org

'Tis the Season

The season of giving took on new meaning this year for SPOHNC's Outreach Administrator and Newsletter Editor, Chris Leonardis. Chris took her love of floral design, and combined it with her love of two organizations that are very close to her heart… SPOHNC, and CP Nassau.

Thanksgiving weekend, the 29th Annual Long Island Festival of Trees to benefit CP Nassau, took place at the Cradle of Aviation in Uniondale, New York. Thousands of people attend the Festival of Trees, a huge holiday event featuring designer decorated trees of many sizes, along with wreaths, gingerbread houses, activities for the little ones, entertainment, costumed characters and even an indoor skating rink! It's quite the event – even Santa and his elves think so!

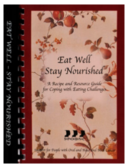
For this year's Festival, Chris donated, designed and decorated a 4' holiday tree, using SPOHNC's colors of burgundy and cream. Her theme this year was white doves and beautiful burgundy blossom stems, accented with snow and icy branches, just for fun. The tree was decorated in honor of SPOHNC, and all of our patients and survivors and their families. Chris really enjoyed the gift of being able to create this special tree for the Festival.

As it turned out – all of Chris' hard work really paid off this year, as her tree was awarded first place in the 4' traditional tree category! She found out about her award when a friend volunteering at the event sent her a photo – what a nice surprise!

In the true spirit of giving and the holiday season, upon a visit to the Festival of Trees on Sunday, Chris' boyfriend, Don, was so excited about the tree, that he purchased it as a Christmas gift for his mother! The tree will shortly make its way to its new home in Westchester and will make a lovely addition to an already beautiful home. This year – the giving was full circle…

Make a Difference. Give a Gift Today.

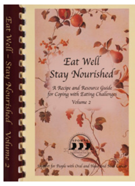
Eat Well
Stay Nourished
A Recipe and
Resource Guide
for Coping With
Eating Challenges
compiled by
Nancy E. Leupold, Survivor, Founder
and President Emeritus



$20.00 includes shipping and handling.

- Recipes & Information About Eating Challenges and Nutrition
- Cancer Journeys of Survivors
- Suggestions and "Tips from the Pros"

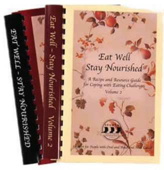
Eat Well
Stay Nourished
A Recipe and
Resource Guide
for Coping With
Eating Challenges -
Volume 2
compiled by
Nancy E. Leupold,
Survivor, Founder
and President Emeritus



$23.00 includes shipping and handling.

- New Recipes
- Chapter Devoted to Fortifying Foods
- Nutritional Information Included with Every Recipe

Two Volume Set
$40.00 includes shipping and handling.



Purchase the Two Volume Set today!

Order at spohnc.org
or contact SPOHNC
at 1-800-377-0928

Delightfully Delicious December Recipes from "Eat Well Stay Nourished A Recipe and Resource Guide For Coping With Eating Challenges"

Compiled and Edited by Nancy E. Leupold, Survivor, Founder & President Emeritus

Roasted Halibut with Potatoes *(from Volume One)*

12 Tbsp. olive oil
2 Tbsp. olive oil to grease the pan
15 oil cured black or green olives – pitted
2 lbs. potatoes
2 garlic cloves, minced
2 halibut fillets – weighs about 1.5 lbs. total weight
¼ c. finely chopped parsley
Salt and pepper

Preheat oven to 400 degrees. Grease 9 x 13 baking dish with olive oil. Chop olives, finely. Place 1/3 of olives in baking dish. Slice potatoes very thin and place in baking dish. Brush with 3 Tbsp. olive oil and sprinkle on 1/3 of the garlic and 1/3 of the olives. Repeat process, then top with last 1/3 of potatoes, 3 Tbps. olive oil and salt and pepper to taste. Set aside the rest of the garlic and oil. Cover potatoes with foil and bake 16 to 18 minutes so they begin to color. Remove foil and bake 10 minutes more until they begin to brown. Mix remaining olive oil and garlic together. Dip fillets in mixture and season with salt and pepper. Place fillets on top of potatoes. Sprinkle with last 1/3 of olives. Return to oven for 10 – 15 minutes or until fillets are flaky when tested with fork. Sprinkle with parsley. To puree, process in blender, adding milk as needed. *Yields 6 servings. 499 calories/serving.*

~ Pat C., MN

Tiramisu *(from Volume One)*

1 lb. mascarpone cheese
5 eggs, separated (at room temperature)
½ c. superfine sugar (scant)
Pinch of salt
Ladyfingers or slices of sponge cake
½ c. strong Italian expresso coffee
4 Tbsp. brandy or rum (optional)
Unsweetened cocoa powder

Beat the mascarpone in a small bowl until soft. In separate bowl, beat egg yolks and sugar – reserving one Tbsp – until mixture is pale yellow and fluffy. Using an electric beater or wire whisk, beat egg whites with salt until stiff peaks form. Fold egg whites into mascarpone mixture. Line bottom of 1 large or several individual serving dishes with the ladyfingers or sliced cake. Add reserved sugar to the coffee and stir in brandy or rum. Sprinkle coffee mixture over ladyfingers or cake slices until the layer is moist but not saturated. Cover with half of egg mixture. Make another layer of ladyfingers or cake slices and moisten with remaining coffee. Cover with remaining egg mixture. Sprinkle with cocoa powder. Refrigerate for at least one hour, preferably more, before serving. *Yields 7 – 5 oz. servings. 590 calories/serving.*

~ Mr. & Mrs. B., NY

Make a Difference. Give a Gift Today.

TIME FOR SHARING...*VIEW FROM THE OTHER SIDE . . . A Caregiver's Story*

Looking at my husband, Chris, now you would never think he had throat cancer. He is the picture of health and thank God, he has been for the past six years. We have celebrated every step of the way and will continue to do so, since we both have a renewed appreciation for life!

So... our story really starts in October 2011. Chris was 48 and I was 45 and we had been married just over two years. Chris felt a small lump on his throat. Needless to say - we did NOT just ignore it. We did a few tests, had a few doctors take a look and nothing really showed up.

Mid February of 2012, while on a trip, Chris asked me to feel his neck as he was thinking the lump seemed larger. It was larger! It had grown to the size of the tip of my pinky finger. When we returned home, we called our doctor and made an appointment.

Throat cancer never crossed our minds! We were both healthy, active and living the dream! We were able to get an appointment to see a Throat Specialist in early April. We did not push for any sooner. You just do not know what you don't know - or what to even ask!

During the month of March - the little lump grew to the size of a LEMON! YES - I kid you not! A Lemon!

April 4th, 2012 - Oh what a DAY! We met with Dr. Kennedy at Geisinger Hospital. He took one look, did a scope of Chris' throat and announced it might be potential throat cancer, but he would need to do a biopsy after lunch. OK - if you are wondering - we really did not have appetites. Scared, confused and speechless we waited the two hours until the test could be completed.

You can never prepare to hear the words: "You have Cancer". All of a sudden, we were tossed into a new world filled with terms, procedures and processes that we knew nothing about and all sounded just confusing, not to mention terrible and scary!

The next week was a whirlwind of follow-up visits, tests, research, questions, etc. The diagnosis was squamous cell carcinoma of the throat and the right tonsil. A tonsillectomy, chemo (cisplatin) and radiation would all be required. The treatment was to remove Chris' tonsil as soon as possible. We began to share the details with family members and close friends - trust me - we needed all the support we could rally and they all came and assisted!

Chris' tonsil surgery occurred on April 19th. First step of this process checked off the list. The next step was for the three-doctor team to meet and discuss the best approach. The TEAM approach was over the top wonderful. Every step of our next few months was coordinated between "our" team.

April 25th – We personally met our team of doctors and nurses and learned more than we ever expected. Both of us felt like we missed a few pieces along the way. Not great news – much more than we ever expected! Long term side effects, pain, high-level meds, follow-ups, treatment plans, etc. We realized the next few months would be very different and difficult for us both! Chris asked me if it was OK to be scared. I said, "it sure is, I am".

Leaving the hospital, totally overwhelmed and unsure of how the next months would be for us, we decided to take a trip! Chris was told to gain weight, as much as he could in the next two weeks. Now there was something we could do! We headed to Key West, FL for a few days of food and fun to try and get our heads around it all. Did I mention food??

The doctors had recommended two books we should read. They give these two books to everyone. Well, reading them by the beach was certainly a positive, but what I was reading was frightening. Honestly, I wished I had them earlier. They were filled with information that we would come to use every day to survive the next 6 months.

So here we go. Beginning of May, Chris has gained weight, he has seen his dentist and taken care of all things required. Again, we had no idea how important a dentist was in the throat cancer process.

We head to meet the oncologist and his team. We will get to know them all very well over the next four months. I am just going to sing their praises at this point. They handled Chris great during his treatments and without them and their support, well I am not sure if I could have held it together. Chris was fitted for his radiation mask and the process is outlined to us. He will need 35 total radiation treatments, five days a week for six weeks. Cancer is at a stage 4, but according to the doctor, Chris' is curable and we caught it in time. Keep eating, but at some point we might need a feeding tube. A WHAT? Yep, that was a new one for us too. Chris kept eating as long as it was physically possible.

May 10, 2012 - He had his first radiation treatment. He made a big calendar with all the days on it and hung it in the kitchen. 34 more to go. On the day of his third treatment we met with our Chemo Doctor, who also would become a "got to" person on a few occasions over the next 4 months for me. Chris will be scheduled for three chemo (cisplatin) treatments. They are the strongest type of chemo, but the doctors feel Chris is healthy enough to endure this level of treatment.

May, 16th he has his first chemo treatment. Besides being scared and nervous, all went OK. I should mention, he is doing this without a port. He has good veins and no one thought there would be a need for a port. So far so good. Food taste a little funny, but he is still able to eat most foods except dry things like pretzels and crackers. He is making lots of shakes to keep his calorie count high and 100 grams of protein a day!

The next day, not knowing what to expect from the chemo, we watch for signs of side effects. He was up and down during the night – but no sickness and only a few sweats and fatigue. Observing all of this for the past week, I tell him he is very brave! He needs to rest often and has a funny feeling in his throat and tummy. We decide that the definition of a "Bad Day" is very different now than it was before in our lives.

They told us the effects of chemo might take a few days. Well, Saturday it hit. He felt terrible! (not the words he was using) Eating was hard today – we tracked the proteins and overall calories to make sure he got

continued on page 9

continued from page 8

enough. He tried to do dinner with friends, but the food did not go down well. He slept most of the afternoon, said it was the worst he ever felt.

Tired and lots of nausea, he starts to sleep more and more. He did eat well today and we got outside for a while. We are tracking his calories and proteins to make sure he is getting enough each day. Whatever he is craving, we get it for him.

Monday morning, Chris is still feeling tired and nauseated. He has a chemo fluids day and radiation. Long day at the cancer center. So, our daily pattern begins to form. I probably did not mention we are an hour from the hospital/chemo/radiation center. This is the part where I tell you - the caregiver role is challenging. Life continues around you and the cancer processes are layered on top. I have a small meltdown. Thinking about what I would tell people about being a caregiver – you wear many hats – nurse, jeep driver, wife, caregiver, cheerleader, princess, maid, communicator, dog walker, etc.

So let's talk drugs. Middle of the third week of treatments the Pain Killer Phase begins. We get our first big scrip filled. So we are new to this too! Let's just say we learned a lot over Memorial Day Weekend. The pain and nausea kicked in and Chris was to the point where he could hardly swallow. He was exhausted and slept for hours at a time. By the end of the weekend he was struggling to get a milk shake down. His frustration level was over the top and he announced to me… "I have had enough, I am not doing anymore radiation, I am not going back!" This is where the caregiver gets pissed off. I tell him to get a grip, you are going back and we are not discussing it again. Those were not my exact words and the tone was stronger, but you get the point.

The morning of Tuesday, May 29th, was a turning a point for us. Chris, my strong, secure, problem solving husband asked me to contact SPOHNC on our drive to radiation. " Ask if they have "someone like me to talk to" he said. YEAH! I felt like I just had a win! I contacted Chris at SPOHNC. She was wonderful!

She connected us to Richard, in the Match Program. He was the perfect match! Richard was 44 when he was diagnosed with similar symptoms. He had been a member of the match program as a volunteer since 2004. Richard had a tonsillectomy, chemo (cisplatin) and radiation as well. He was an eight year survivor!

Chris is a new person! Richard and Chris talk many times over the next few weeks. Plus, we get some new stronger meds and are becoming experts on how to use them. Overall – contacting SPOHNC was a game changer for the rest of this journey!!!

By the end of June, we are counting the final treatments. Chris is sleeping about 20 hours a day. He has lost about 35 pounds and eating is a struggle. Actually, he has been on a liquid diet for the about two weeks at this point. We have upped the meds a few times. He now has 3 to 4 patches and we are using an eye dropped to measure one of the drugs. They shared with us the level of drugs he was on might change his personality. Well, they were right. He also had not been able to drive, due to the drug level, so we had a few challenges.

We are two chemo treatments into the process. Monitoring his temperature has become important. We have been to the emergency room one time due to a spike in temperature and have discussed admitting him into the hospital due to bacteria in his blood. Honestly, I felt like I was on a TV show the night I took him to the ER. I explained he was in a cancer treatment plan and was on cisplatin and his temperature was over 101. Just WOW!, staff was running to assist us!

I am allowed to bring him home, but promise to call if any spike in temperature occurs. His neck is red and raw due to the targeted radiation. We have special cream for it, but it is basically burned on the inside and outside. He is a trouper. He keeps drinking his shakes as long as he uses the magical swizzle medication. We have avoided a feeding tube and a port!

Given all of these items, his doctors are very happy with the progress. End of June, we are scheduled for the final Chemo treatment. Chris' body can only handle a third of the treatment due to health issues surrounding the level of chemo in general. Thursday, June 28th is his last radiation treatment. We celebrate with the staff and they present Chris with his radiation mask. Very emotional! We are done! At least this phase of the process. We need to return the end of July!

I wish it was all that easy. The month of July was difficult as Chris continued to heal from all the "good damage" the treatments did to his throat, neck and body. Coming off the high level of meds was a true "withdrawl" process. We had a lot of rough days and nights with pain, sweats, chills, nausea, fatigue, dizziness and struggles with drinking and the re-introduction of real food. He tried to get outside each day and stay as active as possible. Calls to Richard continued for support during this period. Recovery seemed to be taking a long time and Chris' patience was getting short.

Our end of the month follow-up doctor's appointment went well! The doctors noted that Chris, in his effort to feel better, did rush coming off the level of drugs he was on at the time. Honestly, we had no idea. Chris had the option of going back on some of the drugs or just suck it up for a few days and the withdrawal will be over. At this point, he is a little depressed, he just wants to feel better.

By mid-August we have introduced a few mushy foods. Chris' mouth is still hurting - but he keeps on trying more solid foods. God love him - he is trying so hard. He received a good note from his mentor - inspired him! August 22nd, Chris eats his first Carb Cake! So excited! He is feeling better each day. His weight is holding and his energy level is starting to return. Plus, since most of the drugs are out of his system, he is driving again!

Happy Day! Wednesday, August 29th! We arrived at the doctor's office, after waiting a week to hear the results of the PET scan. I can't even explain the emotional level in the room. Our doctor casually mentions "all looks good." "I will see you in 6 weeks - yeah the PET scan was clear." It was so casual, I had to ask again, "so everything is OK?" The PET showed nothing and the CAT scan showed NO TUMOR. The tears of joy did roll once we got out of the office.

In summary, we experienced emotional and physical highs and lows in the months following this appointment. My husband is a fighter and Richard, his mentor, used sports analogies to focus his positive thinking. Chris and I never thought to ask what his survival odds were in the beginning of our cancer journey. We jumped in and focused on the goal of kicking cancer and moving on with our lives. Later we would find out that in the initial diagnosis, if we would have asked, the doctors would have given us a 50/50 chance of survival.

continued on page 10

Connect with SPOHNC's "group" on Facebook

continued from page 9

There is a lot to be said about the power of positive thinking and the strong support group in place to keep you focused. As a spouse, who was in the position of a caregiver, it is difficult. Most family and friends would ask me, "how is Chris, how is he doing, etc?" I wanted to just shout - "IT HAS BEEN HARD, THE MOST CHALLENGING THING WE HAVE EVER DONE!" Honestly, I never shouted that at anyone, but it sure was nice when someone asked me, "How are you doing?" I try to remember this whenever I meet someone who is in the caregiver role.

~ Connie Lunt
connielunt@gmail.com

Here's something I put together given my experience in the caregiver role. I share these with people if asked how to approach being a caregiver.

H *- Have Patience - This is a learning process for you and the patient.*

E *- Everyone wants to know. Designate a spokesperson to share info and respond to calls, etc.*

R *- Read the two books that are recommended (Meeting the Challenges of Oral, Head & Neck Cancer and We Have Walked in Your Shoes). Both are availiable through SPOHNC.*

E *- Every patient has difficult moments. You might have to get tough and push them.*

F *- Friends and Family - It will take a Village - get yours in place and ask for support.*

O *- Open your mouth! Do not be afraid to ask! Any question is OK! Ask them to spell the big words!*

R *- Roles change - you will wear many "Hats"- some of them will be new to you!*

Y *- You need to take time for yourself - Breath - do something that makes you feel good.*

O *- One important phone call - SPOHNC! You and your patient can receive support!*

U *- Use your smile! Nurses and doctors will be your best friends. Treat them with respect and say thank you!*

News from The Board Room

Contributed by Guest Author,
Eugene Myers, MD, FACS, FRCS, Edin (Hon)

SPOHNC, and its courageous Founder, Nancy E. Leupold have been an inspiration for me in my career as a head and neck surgeon. I've had the pleasure of working with Mary Ann Caputo, Executive Director and Chris Leonardis, Editor of the Newsletter, in a variety of ways and it's a great honor for me to have recently been appointed to the Board of Directors.

I was delighted when Chris invited me to tell a bit about some honors I've received in 2017/18. I supposed that having a Gold Medal created in one's name – Eugene Nicholas Myers Multidisciplinary Salivary Gland Society (MSGS) Award would be at the top of my list. I've added this to my other medals including the Grand Gold Medal of the Comenius University – Slovakia (2006), the IFOS Gold Medal – Brazil (2009), and the Confederation of European Otolaryngology (CEORL) Medal for Education in Head and Neck Surgery – Prague (2017). I also received the Life Time Achievement award from the Asian Society of Head and Neck Oncology (photo).

In 2018 I delivered the Grinspoon-Montgomery Lecture at the Massachusetts Eye and Ear Infirmary/Harvard Medical School. It was very meaningful for me since Bill Montgomery was an important role model for me during my residency there.

I was the Guest of Honor at the Congress of the Confederation of European Otolaryngology (CEORL) in Barcelona. It was particularly exciting since it was the beginning of the demonstrations by the Catalonian separatists against the Spanish Government in 2017. I was also the Guest of Honor of the Combined Meetings of the Triological Society in New Orleans in 2017.

I've dedicated a significant segment of my career to International Activities. I have visited more than 100 countries, mostly at the invitation of colleagues to lecture and operate. I'm an Honorary Member of 22 National Societies. I've been the Honorary President of the Balkan Society of Otolaryngology – Head and Neck Surgery since its revival in 2001. I attended their Congress in Varna, Bulgaria (2018) and gave several lectures. I've been Moderator of several Panels and Mini-seminars sponsored by the Brazilian Society of Head and Neck Surgery and was the Special Invited Guest Speaker at the meeting of the Caribbean Association of Otolaryngology in Barbados (2018).

I haven't neglected the Editorial part of my life. In 2017, Volume 5 of my series – Master Techniques in Otolaryngology – Head and Neck Surgery: Facial Plastic Surgery (Larrabee) was published and in 2018, Volume 6 – Otology and Lateral Skull Base Surgery (Roland) was published; both by Wolter Kluwer/Lippincott Williams and Wilkins. I was invited to write the FOREWARD to four textbooks, to bring my total to 12 FOREWARDS. Operative Otolaryngology – Head and Neck Surgery 3rd Edition, Co-edited by Eugene N. Myers and Carl Snyderman was awarded High Commendation for Editorial Excellence by the British Medical Association. I was thrilled to learn that Dr. Robert Witt dedicated his book, Surgery of the Salivary Glands, to me.

Overall, not too bad for an old guy who officially retired from the University of Pittsburgh School of Medicine in 2015, but has kept his hand in a specialty which has provided great gratification. I'm so proud of my family and appreciate their support and love which allows me to continue to serve my specialty.

> **"Thanks for providing such valuable resources to cancer patients in the community."**
>
> *~ Kathleen D.*

CHAPTERS OF SPOHNC
(125+ and growing!)

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

ALABAMA
BIRMINGHAM, HUNTSVILLE, MOBILE

ARIZONA
CHANDLER, GILBERT,
PHOENIX, SCOTTSDALE

ARKANSAS
NORTHWEST

CALIFORNIA
BERKLEY,
NEWPORT BEACH,
ORANGE-UCI,
SAN DIEGO, SOUTH SAN FRANCISCO,
SANTA MARIA, STANFORD, VENTURA

COLORADO
COLORADO SPRINGS,
DENVER, WHEAT RIDGE

DC
GEORGETOWN

FLORIDA
DEERFIELD BEACH, FT MYERS,
JACKSONVILLE, NAPLES,
PALM COAST/NORTHEAST,
WINTER PARK

GEORGIA
ATLANTA,
SAVANNAH

IDAHO
MOSCOW

ILLINOIS
EVANSTON,
MAYWOOD, MORRIS, SPRINGFIELD

INDIANA
AVON
SOUTH BEND, TERRE HAUTE

IOWA
DES MOINES

KANSAS
KANSAS CITY

LOUISIANA
BATON ROUGE, NEW ORLEANS

MARYLAND
BALTIMORE-GBMC, BALTIMORE-JHMI,
LIBERTYTOWN

MASSACHUSETTS
BOSTON, CAPE COD,
DANVERS

MICHIGAN
ANN ARBOR, SAGINAW, WARREN

MINNESOTA
MINNEAPOLIS, ST. PAUL

MISSOURI
ST. LOUIS/DPCC

MONTANA
MISSOULA

NEBRASKA
LINCOLN, OMAHA/MCC

NEW JERSEY
CAMDEN, ENGLEWOOD,
LONG BRANCH,
PRINCETON/UMC,
TOMS RIVER

NEW YORK
BUFFALO, MANHATTAN/BI,
MANHATTAN/MS, MANHATTAN/NYU,
MIDDLETOWN, NEW HYDE PARK,
ROCHESTER, STONY BROOK, SYOSSET,
WHITE PLAINS

NORTH CAROLINA
DURHAM

OHIO
CINCINNATI, CLEVELAND,
DAYTON

OREGON
MEDFORD

PENNSYLVANIA
DUNMORE,
HERSHEY, LANCASTER,
PHILADELPHIA/UNIV. PENN HOSPITAL,
YORK

SOUTH CAROLINA
GREENVILLE (UPSTATE)

TENNESSEE
NASHVILLE

TEXAS
AUSTIN, DALLAS/BICMC,
DALLAS/NCC, DALLAS/UTS,
FORT WORTH, SAN ANTONIO

VIRGINIA
CHARLOTTESVILLE, FAIRFAX,
NORFOLK, MECHANICSVILLE

WASHINGTON
SEATTLE

WISCONSIN
APPLETON

> ***"We are grateful***
> ***that you are there..."***
>
> ***~Lewis & Amy B.***
> ***SPOHNC Palm Coast NE, FL***
> ***Chapter Facilitators***

S•P•O•H•N•C P.O. Box 53 Locust Valley, NY 11560-0053 1-800-377-0928

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

MEMBERSHIP APPLICATION
SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER, INC.
P.O. Box 53, Locust Valley, NY 11560
Membership includes subscription to eight issues of *News From SPOHNC*

Name________________________________Phone (________)________________________

Address______________________________Email Address___________________________

Address____

City____________________________State______________Zip____________________

Please Check: Survivor ____Friend ____Health Professional (Specialty) ______________________________

First time member__________ Returning member________

ANNUAL MEMBERSHIP
☐ $30.00
☐ $35.00 Foreign (US Currency)

CONTRIBUTIONS
☐ Booster, $35+ ☐ Donor, $50+ ☐ Sponsor, $100+
☐ Patron, $500+ ☐ Benefactor, $1,000+ ☐ Founder, $5,000+
☐ Leaders Circle, $10,000+ ☐ Visionary Circle $15,000+

Call 1-800-377-0928
to become a member and make a contribution by credit card or order online at www.spohnc.org

---

SUPPORT FOR PEOPLE WITH
ORAL AND HEAD AND NECK CANCER
P. O. BOX 53
LOCUST VALLEY, NY 11560-0053

NON-PROFIT
ORGANIZATION
U.S. POSTAGE
PAID
LOCUST VALLEY, NY
PERMIT NO. 28

ADDRESS SERVICE REQUESTED

Remember!

Make Your Gift to SPOHNC Today

Because...

Together, we heal