

NEWS FROM S•P•O•H•N•C



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

NOVEMBER 2019



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A PROGRAM OF SUPPORT
FOR
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Taking The Healing Aspect of Music Further

Sara Chigani, MA, MT-BC

“Oh, I’m not musical” or “I only play the radio” are a couple of typical answers I get after introducing myself as a music therapist. Yes, music is healing and as a board-certified music therapist I take the use of music to promote healing a bit further.



You may not realize it, but our bodies are innately musical. Our heartbeat is the most fundamental beat our body makes and is unique to you. Your unique heartbeat is a rhythm cultivated by the unique size and orientation of all your different organs, valves, and physiology, with your heart being the instrument. Let’s look at your walk as another example, which is also unique to you. Have you ever been able to know who’s walking around just by listening to the sound of their footsteps? That person’s walk is the musical combination of using their shoes, steps, feet, legs, and sometimes their pants to create a unique sounding walk. Lastly, let’s think about our speech. The way we speak becomes a distinct melody which we use to express ourselves. We may use strong louder tones when we express anger, fast higher tones when we are excited, and perhaps slow tones when we are sad, however, that’s unique to each person, too. So, as you can see, whenever anyone responds with “oh, I’m not musical,” I say, “but you are!”

As a board-certified music therapist, it is my job to get to know each of my patients and understand what kind of music they gravitate towards, how they use music in their life, how we can use music to address specific health goals that present a

need and create a plan of action going forward. The music that is innate within us is unique to you, so each time I meet a new patient my clinical process is specifically designed for you. That’s what makes music therapy such a well-rounded therapy, because I don’t focus on just the diagnosis, I focus on what makes you, you. As a result, the goal(s) to be worked on during music therapy may not always be the diagnosis itself; it may be outlying symptoms that presented as a result of the diagnosis or something completely unrelated. For that reason, the things we work on in music therapy may be emotional, cognitive, physical, or even spiritual. Take, for example, a person who is admitted to the hospital to receive a bone marrow transplant for a cancer diagnosis. This procedure involves transplanting blood stem cells that travel to the bone marrow to stimulate the growth of new marrow. Typically, when admitted for a bone marrow transplant, that hospitalization is long, usually several weeks to one month. I have met several patients in that very situation and who have begun experiencing depression and anxiety because of their long hospitalization. I can’t give a typical example, because it is unique each time, but sometimes patients experience a loss of purpose during their hospitalization.

Patients usually have a busy life before they are admitted and that all comes to a stop. They have lots of time to think, sometimes a decrease in visitors, and a lot of times patients have to take a break from their job. After I meet the patient, I introduce myself and we typically talk for a bit. I may learn that they have always wanted to learn a certain instrument, but never had the time. That is where I present their opportunity. Learning an instrument that you’ve always wanted to learn, while hospitalized, gives you control back, you’re learning songs you enjoy, and it is a great workout for your brain. Now you might be saying, “so you’re kind of like a music teacher?” Well, yes and no. I am teaching you how to play an instrument, but unlike a music teacher, my goal isn’t for you to become the next Beethoven or John Lennon. My goal in teaching you an instrument is to make learning accessible to you and to help you gain a sense of accomplishment, proving to yourself that you are capable and able to overcome obstacles. If you end up becoming the next Beethoven or John Lennon that would be icing on the cake!

For individuals with oral, head and neck cancer, music therapy can be a great tool to promote communication and expression. The great thing about music is, it can convey a message through just instruments. When you listen to classical or jazz musicians, you can still form an idea of what they are trying to communicate to their audience. We can do the same in music therapy. You may encounter a music therapist that conducts what’s called a “drum circle.” Typically, the music therapist arranges various percussion instruments in a circle and people can start on one instrument and change instruments, as they need. Drum circles are a great place for people to express themselves in a non-verbal way. You are

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communicating a message on your instrument as others listen and respond to you on their instrument. It may sound a little funny, but it's amazing to hear how groups of people come together and engage through the music. Not only is it a great way to communicate, but drumming can also decrease anxiety, promote pain relief, improve circulation, lower stress, and promote movement.

I have also worked with patients in the hospital with varying diagnoses, other than cancer. Music is processed throughout the entire brain, which then sends messages to the rest of your body allowing your body to move to the music. As a result, music therapy is a fantastic tool to help rebuild parts of the brain that may have been damaged during a traumatic event. When a person has a stroke, it can impact their ability to communicate. Language is processed in the left side of our brain. Experiencing a stroke that impacts the left side of the brain can affect a person's ability to speak, which is a disorder called aphasia. Because we use our entire brain to process music, it is not uncommon for a person to still be able to sing after experiencing a stroke. Music therapists use this fascinating ability to help rebuild the damaged areas of the brain by using the surrounding areas that remain intact. So, even though a person may be unable to state their name, we can form their introduction into a song allowing the person to express what they want to say and, in time, making the correlation between singing and speaking.

Remember how I mentioned your walk is musical? With that in mind, let's take the previous example of a person who encountered a stroke. You may have heard that a stroke can also impact your ability to move one side of your body, specifically your arms and/or legs. Music and movement have such a strong connection, so strong that we use that to help regain a person's ability to move after a stroke. Have you ever tried to listen to a song with a strong beat and not moved to the music? That's because music is predictable. The beat is steady and remains the same, which can help promote coordination. Let's take, for example, the army. If you have ever heard or seen a group of soldiers march together, do they march in silence? No! That would be such a difficult task to get a group of men and women to march in unison without some sort of beat. I think the beat that everyone is most familiar with is, "left, left, left, right, left." Ah! Now we're all together!

Even though we do a lot of work with patients directly, I have also worked with the patient's caregiver(s) as well. Going through an illness is extremely difficult for the patient; however, sometimes it's just as difficult, if not more so, for the caregiver(s). In the hospital, I often encouraged the caregiver(s) to take a break, whether that is a 5-minute walk down the hall or 20 minutes in the waiting area to read a book. As music therapists, we can also work with the caregiver(s) just as we work with the patient. Not too long ago, I had the opportunity to work with a woman and her husband. The woman had just experienced a traumatic brain injury and was not able to engage with her husband in a lot of ways. After talking with the husband, I discovered a favorite musician of theirs. In talking a bit further, I learned that he also played a little bit of guitar. In our next meeting together, I brought in my guitar and the chords and lyrics to one of their favorite songs by that very musician. As he began to play I joined by singing along. After a couple of times practicing the song, the woman, who typically didn't acknowledge very many people, turned her head, looked at her husband and gave

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him a faint smile. Not soon after, the husband shed a few tears sharing how difficult their journey had been. As I was present with him, he had a safe place to release his emotions that he had been hiding, so he could be strong for his wife. However, it allowed them an opportunity to engage with each other in a manner that reminded them of who they are rather than their medical hardships.

It may sound like fun and games, but to become a board-certified music therapist it takes a lot of studying and practice. Music therapy is an actual major in college, that's 4+ years of school. A music therapy student is a full-fledged music student who takes all the required music classes like music theory, ear training, ensembles, and music history, just to name a few. In addition to all the music classes we must take, we also take biology, anatomy/physiology, psychology, and sociology. During school, we are required to learn the fundamental music therapy instruments: guitar, piano, voice, and percussion. We are tested on our ability to play these instruments, but also how we use them with the various patients we may meet. Throughout our schooling, we attend "practicums" in various settings and observe and work with a supervising board-certified

music therapist to learn how they work in the setting they do. I was fortunate to have a wide range of practicum experiences that ranged from a memory care facility for those with severe dementia, children's hospital, foster care facility for adolescents, and an elementary school. As you can see, music therapy is practiced in many different facilities with a wide variety of people. After we finish our education, we are required to work in a six-month internship where we mature from student to professional. Finally, once those requirements are complete, we take a board exam, which if we pass, we can officially call ourselves a "board-certified music therapist" or "MT-BC".

Because music is so widely used in many different ways to promote healing, it can be common for a person to be mislabeled as a music therapist or an activity mislabeled music therapy. It is important to be aware of who you are working with and their training. Believe it or not, music can negatively impact a person if used incorrectly or by someone without training. For example, music has such a strong connection to our emotions, sometimes a specific song can make us cry or feel extremely sad. It is what happens after hearing that song that

can promote healing and that's why it's important to have a trained music therapist there to experience the emotions with you and help you work through them. Music is a powerful healing tool, but it's how you use it that can take the healing aspect further. To learn more about music therapy, or to find a music therapist in your area, please visit the American Music Therapy Association website at www.musictherapy.org.

Editors Note: Sara Chigani, MA, MT-BC is a board-certified music therapist based in Dallas, TX. Sara received a Bachelor's of Music Degree from Berklee College of Music in Boston, MA and a Master's of Arts in Music Therapy from Texas Woman's University. Sara completed a rigorous music therapy internship at Children's Medical Center – Dallas and has clinical music therapy experience ranging from neonatal to end of life. She collaboratively began the music therapy program at Baylor University Medical Center – Dallas where she worked with both inpatient and outpatient populations. Sara currently works at KidLinks in Dallas, TX where she provides music therapy for children in need.



Survivor & Chapter News

Local support groups find ways to laugh through cancer

Judy Churco felt utterly alone.

A cancer diagnosis took a normal life from her. She could no longer eat many foods. It made speech sometimes hard. It left her with scars. While she had family — her children and her husband — who stood by her side, people did not understand what she went through.

Until she formed a support group for those with similar cancers. The group started small, but it gave Churco another family. One where they could bond over the losses from cancer and find something almost surprising at a cancer support group — the ability to laugh.

Churco's cancer diagnosis came in 2002. Oral cancer.

Treating the cancer required multiple surgeries. She ended up losing a quarter of her tongue and lymph nodes out of her neck.

The cancer returned in 2005 and 2009, costing her more of her tongue and more lymph nodes. "It was horrible," Churco, 75, said. "It's been a horrible time for me."

Through her church, she met another person with the same type of cancer, which was "really wonderful," Churco said.

It allowed them to bond over different treatments, to talk about the effects of the cancer. In

2010, Churco's doctor put her on a strong radiation, called fractionated radiation. Her friend did not go through it and eventually passed away.

Churco credits that radiation with saving her life. But without her friend, she was alone again. And the cancer had taken more than part of her tongue. It took

her ability to eat normally. Because of the radiation, she cannot go out in the sun. She no longer has "a good life," she said.

So Churco started a branch of Support for People with Oral, Head and Neck Cancer, or SPOHNC. There were two already in Baltimore, which she attended, but none in Frederick, MD.

Her church lent her the space for the group. But the first two times, no one showed up, she said.

Then a lady showed up. And the group began to grow. There's about 16 people now, although participation varies by meeting. Not everyone has the same type of cancer. There are people with tongue cancer. Others with tonsil cancer. Sinus cancer, cheek cancer, lymph node, throat, she said.

"Head and neck cancer is there," Churco said. "It's out there for everyone to see." One of the regular participants is Jodie Schwam. Her cancer took her ability to eat solid foods, except for watermelon,

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Schwam said in an email.

"Attending helped me to feel that I was not the only one with problems," Schwam said in the email. "Going to this group has been a lifesaver. You learn that you are not alone."

Churco's group meets the second Wednesday of every month and is one of the many cancer support groups in Frederick County. Some, like hers, are specific to a type of cancer. Others invite anyone with cancer. Some even target the caregivers of people diagnosed with diseases.

There's one on Fridays. Another on Saturdays. Frederick Health Hospital, formerly known as Frederick Memorial Hospital, runs ones for breast cancer, ovarian cancer and prostate cancer. There's one for women going through changes to their appearances due to cancers.

Terri Dawson co-leads a group with Larey Richmond at Monocacy Valley Church in Ijamsville every Friday. The group is open to those with cancer, in general. It's been around for about 10 years and was started after a request from a man with cancer.

Steve Engle approached Dawson in 2009. He had cancer and wanted to attend a support group, but he only found ones for breast cancer.

So Dawson and Richmond created a group for Engle. Richmond is a licensed counselor, which meant she was able to help those in the group process feelings like grief or stress.

Engle died in 2012, but the group continued after him, Dawson said. He came until the end. Over the years, Dawson said she and Richmond have commented about how strong each of the group members are.

"I think we've really helped them, and they've really helped us too," she said.

People often come to the group after they are first diagnosed, Dawson said. Participation often varies. Sometimes only one person shows up. Other times there are seven to 10 people. Dawson and Richmond are there when people come.

"Each Friday, we're here, and we don't care if one person shows up or 20 people show up. We're going to be here to help them any way we can," she said.

Although the support group is held in a church, similar to Churco's, those who come do not need to be a member of the

church. And it is open to anyone with cancer, and they've had about everything. Brain cancers, multiple myeloma, liver, pancreatic, lung, leukemia, breast.

"That was the one thing that Steve really, really wanted to make sure that we did it so any type of cancer diagnosis is welcome to come because there are just not too many out there," she said.

Another group for anyone with cancer meets every second Saturday at Zion Lutheran Church in Middletown. The support group started out as a way to better respond to people in the church and community with cancer, said Pastor Marv Tollefson, who leads the group.

Like Dawson's group, the one at Zion Lutheran is open to anyone with cancer or those in remission. Even caregivers.

"Any age, anyone," Tollefson said. Tollefson understands the need for a support group, he said, as he is a lung cancer survivor himself.

"Cancer, you might say, is such a scary, unnerving illness," he said.

The group leaders went to training in Philadelphia to learn to better lead a support group. The group offers faith-based support and a safe place to pray. "Our expression is we'll walk along side you," he said.

The cancer support groups are there for people in remission as well as those actively living with the disease. Dealing with losing a member of the group is part of leading a support group.

Churco said that the group tries to gather around when someone dies. If they can, they'll attend the funeral. She might also call the family or send a card when a person dies, she said.

The Monocacy Valley Church's group learned how to handle losing a member when they lost founding member Engle to his cancer, Dawson said. He attended until the end. "He never missed it," she said.

Dawson keeps a memory board in her office at the church. Every time someone in the group passes, she lights a candle.

There is a balance between giving hope while also understanding the struggles that those in the group face, she said.

Despite losing some members, the cancer support groups are often relaxing for those who attend. At Churco's, the

word to describe it might be fun. She said that those who attend often find ways to laugh with each other.

Being able to laugh and relax around people who went through similar trials is the reason people come back to her group, she said.

Churco also benefits. Even if people have different cancers, they affect each of the group members similarly. For Churco, who was once alone with her disease, she's found a new family.

Editor's Note: Reprinted with permission of The Frederick News-Post as published on Oct. 29, 2019



photo courtesy of PJ Jordan, NSVN Caregiver Volunteer and amazing photographer

"There's nothing like face-to-face interaction with others who are walking similar paths"

~ Linda C.

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Chapter News

Head and Neck Cancer Awareness Week

University of Minnesota Head and Neck Cancer Survivor's Conference

The Minneapolis, MN SPOHNC Chapter attended the University of Minnesota Head and Neck Cancer Department's 2019 Head and Neck Cancer Survivor Conference.

Every year the University sponsors a half day conference on current developments and treatments for head and neck cancer. Throughout the morning four survivors told their story. There were four breakout sessions covering: Dentistry's Role for Those Diagnosed with

Head and Neck Cancer, Long Term Radiation Effects, Hearing Loss from Chemo and Radiation, All Things Swallowing, Lasting Effects of Surgery and Chemotherapy, Immunotherapy, and Health Promotion in Survivorship.

The conference was dedicated to the memory of Justin Amand, who passed away March of this year due to complications from his cancer. He was a great supporter of the conference and

Co-Facilitator of the Minneapolis SPOHNC Chapter. We miss the encouragement he gave each of us as he fought his own battle with the disease.

In addition to giving a short talk about SPOHNC we had an informational table that stressed the importance of a support group. Many interested people stopped to ask questions or to talk. SPOHNC's book "We Have Walked in Your Shoes" and handouts on diet were popular items.

The Minneapolis SPOHNC Chapter had seventeen members attend. Total conference attendance was about one hundred. Overall a very informative event for Head and Neck Cancer Awareness Month.



Words of Wisdom... Of Grief and Gratitude

I have had several conversations with people about my column from last week, where I wrote about how the season of Fall reminds us that loss and letting go are a natural and inevitable part of life. A couple of people said this is precisely why they don't like Fall because it does remind them of loss. I understand that because feeling the sadness we have about the losses we have experienced is never easy. A question I often get as both a pastor and therapist is some version of, "Do I really have to talk about and feel my sadness and grief, or is it best to just try not to think about it, in hopes that it will go away on its own?"

Take a moment and think about the people in your life who you think of as wise, the people who you might describe as "old souls." I know for me, the people I think of in this way, are also people who have been through a lot and have come out the other side wiser and deeper, both emotionally and spiritually. They have been through hard times, including challenge and loss, and have emerged more grateful and wiser about life.

So while none of us desires experiences of grief and loss, they are, of course, inevitable. Our only choice is how we will carry them.

Francis Weller, a well-respected psychotherapist and grief expert, says all of this much better than I am saying it here. And so I will close with a long quote from

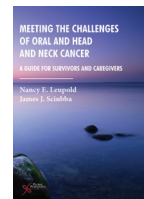
him. May his wisdom help us to see that it is in the way we carry our losses that enhances our capacity for compassion and gratitude.

"The work of the mature person is to carry grief in one hand and gratitude in the other and to be stretched large by them. How much sorrow can I hold? That's how much gratitude I can give. If I carry only grief, I'll bend toward cynicism and despair. If I have only gratitude, I'll become saccharine and won't develop much compassion for other people's suffering. Grief keeps the heart fluid and soft, which helps make compassion possible."

Editors Note: This column first appeared in the Weekly Words of Wellness, a weekly column written by the Rev. Dr. Scott Stoner, the Founder and Director of the Living Compass Wellness Initiative, and is reprinted with his permission. You can out more at www.LivingCompass.org.



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HEAD AND NECK CANCER NEWS

Immunotherapy Responses Differ by Sex, Study Says

October 25, 2019 -Immunotherapy responses may not be equal between the sexes, according to new research.

The new meta-analysis of the role of biological sex in cancer treatments was presented at the European Society for Medical Oncology (ESMO) Congress 2019. The research followed up on work published last year in *The Lancet Oncology*.

The ESMO results showed a benefit for women with immunotherapy-plus-chemotherapy, while the previous results showed better overall survival for men with immunotherapy alone, according to the study.

Lead researcher Fabio Conforti of the Istituto Europeo di Oncologia, Milan, Italy, told *CancerNetwork*® that the fundamental differences between the sexes could mean a whole new way to understand immunotherapy dynamics.

“Since this has an important impact on multiple elements and function of both innate and adaptative immune system it is plausible that some immunotherapeutic strategies are more effective in women and others in men,” said Conforti.

“This is the main message of our work: given the sex dimorphism in response to anti-cancer immunotherapies, it is necessary to properly assess effectiveness of each new therapeutic strategy in both sexes, in order to improve treatment efficacy for both sexes,” he added. “For example, ensuring a proper accrual of women in randomized clinical trials.”

The ESMO abstract showed a search of PubMed, MEDLINE, Embase, and Scopus for all randomly controlled trials testing anti-PD-1 or anti-PD-L1 treatments for patients with advanced or metastatic solid tumors, and either given alone or in combination with chemotherapy.

The 16 phase III trials included monotherapy versus standard chemo in 9,291 patients. The trials included a variety of tumors (2 melanoma trials, 8 for non-small cell lung cancer (NSCLC), 2 in head and neck squamous cell carcinoma, 2 gastric cancer studies, and a study apiece in kidney and urothelial cancer.

Fifteen of the 16 studies showed men

with better pooled overall survival (OS) than women in the studies: for men the hazard ratio (HR) was 0.73 (95% CI, 0.69-0.78), while for the women the HR was 0.86 (95% CI, 0.78-0.94). (This follows, and echoes, the same team’s results published last year in *The Lancet Oncology* journal, among more than 11,000 patients administered immune checkpoint inhibitors).

But in 5 of the studies examined, the combination of chemo-plus-immunotherapy was compared against chemotherapy alone in 2,979 patients. (Four of the studies were in NSCLC and 1 in small cell lung cancer).

In these five studies, the women showed “impressively larger OS benefit,” according to the abstract: the pooled OS HR was 0.50 (95% CI, 0.41-0.60), compared to an HR of 0.76 for men (95% CI, 0.66-0.87).

Conforti said the results of the benefits for women could show different characteristics of tumors based on biology of the sexes – and it could also explain why some treatments work better than others currently.

“It could be hypothesized that such heterogeneity of response is due to the ability of chemotherapy to increase the mutational burden and neoantigenic load of female lung cancer tumors that are

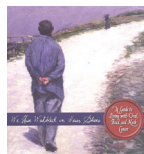
statistically significantly lower than those of male tumors, with this being also a potential biological rationale to explain the lower efficacy of anti-PD-1 alone in women,” said Conforti. “Furthermore, different efficacy of chemotherapy in modulating the anti-cancer immune responses of men and women could be speculated.”

Conforti further told *CancerNetwork*® that they are looking at identify at sex-based differences down to the level of molecular mechanisms of anti-cancer immuno-responses. Preliminary responses will be presented at the upcoming Society of Immunotherapy of Cancer meeting.

“To date, we have preliminary results showing relevant differences in the cell-type composition of the intra-tumoral immune-infiltrates of tumors arising in men and women,” said the researcher.



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

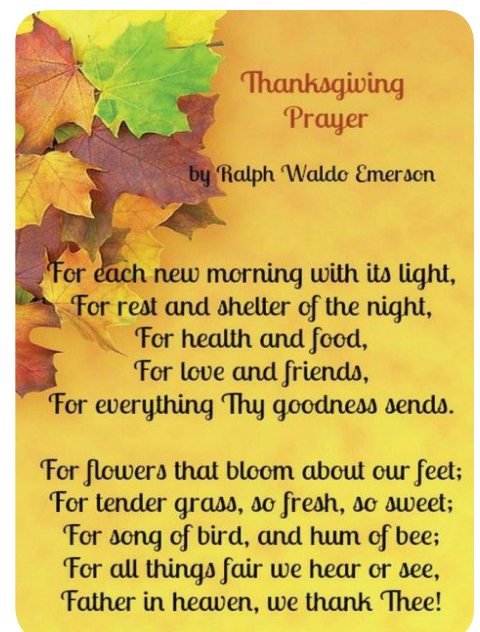


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**Warm and Yummy Thanksgiving Recipes from
“Eat Well Stay Nourished A Recipe and Resource Guide
For Coping With Eating Challenges”**

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

Potato Casserole (from Volume One)

7 Tbsp. butter, divided
½ c. onions, chopped
2 lb. frozen shredded hash brown potatoes,
defrosted
1 8 oz. package cheddar cheese, shredded
1 10 oz can condensed cream of chicken soup
1 tsp. garlic powder (optional)
1 pt. sour cream
Buttered cracker crumbs or corn flakes (optional)



Melt 2 Tbsp. butter in frying pan and saute ½ c. onions. Add 4 more tablespoons butter and heat until melted. Place defrosted hash browns in large bowl. Add shredded cheddar cheese, cream of chicken soup, garlic and sour cream. Pour in onion-butter mixture. Mix well. Pour into a 13 x 9 casserole dish. Put buttered cracker crumbs or corn flakes on top if desired. Bake at 350 degrees for one hour and 15 minutes. Yields 8 - 7 ounce servings. 457 calories per serving.

~ Member of SSF, PA

Cream Cheese Chicken Soup (from Volume Two)

1 small onion, chopped
1 Tbsp. butter or olive oil
3 c. chicken broth
2 medium carrots, chopped
2 medium potatoes, chopped
2 c. cubed, cooked chicken breasts
2 Tbsp. chopped fresh parsley or 2 tsp. dried
Salt and pepper to taste
8 oz. cream cheese, cubed



Saute onion in butter or oil. Add broth, carrots and potatoes and bring to a boil. Reduce heat and simmer 15 minutes. Add chicken and seasonings. Combine milk and flour and add to mixture. Bring to a boil. Cook and stir until thickened, about 2 minutes. Reduce heat and add cream cheese. (Use amount of cream cheese dependent upon your taste and the calorie content needed). Cook on low heat, stirring occasionally until cream cheese melts. This soup can be pureed in blender for easier swallowing. This soup is very creamy. Serves 8. 251 calories per serving.

~ Susan B., IN



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Time for Sharing... Music Therapy

My husband Mel lost his nose to cancer. He wears a surgical mask. After trying to wear several kinds of prosthetics he gave up and we stayed home. In a high school cancer support group, we created and did a project for a classmate who had cancer. We got some band members still playing music along with a few volunteers and made a video for our friend. They sang "Hungry Like a Wolf" and it was great. We videoed the song and posted it on his timeline on Facebook. He was taken aback and so touched that his classmates got together and did this for him - it's now gotten well over 1,000 views.

It was at that time we were invited to



see one of the bands involved. After that, Mel began to come out of his shell so I bought him some Cancer Sucks baseball caps and matching T-shirts. The cancer sucks hat also help when you cannot hide your cancer scars.

It broke the ice - when he would walk in he was not stared at. Instead he was being greeted by high fives and hugs. This is good I thought...so we began to go out at least once a week and a transformation began. The next thing I knew he was ordering food and a soda, something he'd never done. Before, he would just listen to the band hungry and thirsty but now what I was seeing was my Mel come alive again. I will never forget coming back to the table where he had ordered a slice of pizza and was told he ordered it. He cut it into tiny pieces and ate it with a fork.

We have met some remarkable people and great bands and the music has been so healing for both of us. Mel and I mentor cancer patients, which can easily burn one out. Photography and listening to local bands have helped us keep that from happening.

We now share all of it with a select group of patients and they seem to love it. Best of all my husband is back and music is making his life much more bearable. He also had cervical neck surgery after cancer

which saved him from being paralyzed but left him with tingling in both legs, arms and hands. He says the band music helps him forget all the bad things for a few hours. So (patients, caregivers) if you can find a way to get out for a few hours and listen to a good local band where you live, we highly recommend it. This is our story.

~ PJ Jordan

pjjordan176@yahoo.com



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In Memoriam *Maria Folchetti*

SPOHNC is devastated and deeply saddened to share news of the passing of one of SPOHNC's Syosset, NY Chapter Support group long time attendees – Maria Folchetti. Maria was a beautiful, vibrant woman, and a true warrior – fighting her battle for almost 10 years through so much adversity and pain. She never ever gave up – and she never complained to anyone.

Maria was a brilliant bright light at each SPOHNC Chapter Support group meeting she attended, sharing her courage with all who came to the group for the love, warmth and support of others while on their cancer journey.

Maria and her amazing family came to SPOHNC seeking support through a phone match, and soon became regular attendees at our SPOHNC Syosset, NY support group. For Maria, support was a family affair. She was most often joined by her husband and daughters and son, and sometimes, her grandchildren even came along – especially for the special events hosted by the group, including our Tasting events, and especially the SPOHNC Syosset Holiday gatherings, where Maria's delicious dishes were always a hit.

Maria's daughter, Angela, shared some beautiful words with SPOHNC about her mother in the days following her passing...

"My mother, Maria, lived a beautiful and full 63 years of life. From a young age, my mother decided that her life calling was to get married and to have a family. She followed her dream and dedicated her life to being the greatest wife and mother.

About 8 years ago, my mother started her battle with cancer, but it never interfered with her love for life and her bright spirit. She continued to live each day to the fullest and still enjoyed shopping, traveling with my dad, she even ventured to St. Marteen (the country) to get a haircut a few times and thought it was perfectly normal!

On her journey, my mother, Maria, taught friends, family members, acquaintances, doctors, nurses, other patients, and even strangers how to appreciate the little things in life. When she lost her ability to eat by mouth, she was grateful for her feeding tube. Despite

her struggles, she would still prepare big, delicious dinners for her family and friends even though she could not enjoy them herself. She loved watching others enjoy her food. She was not angry.

When my mother was presented with challenges that most people wouldn't



know how to deal with, she showed us all a different way. She always kept a positive attitude and never complained. No matter what life brought her way, she was resilient and always found a way to adapt and create what she would call her "new normal."

In terms of faith, my mother found God in people. Each person she met on her journey was sent from God. She welcomed her daily nurses in and treated them like family. My mother had a difficult



time praying, especially when she was in pain. She spoke of her love for God but could not connect to prayer at times. Two nights before she passed, she initiated a conversation about life, death, faith, and prayer with her night nurse, Maritisia. In that one powerful conversation, she connected to God our Father and together, my mother and Maritisia said the Lord's Prayer together along with other personal prayers.

My mother was and is truly amazing. I told her every day how proud I was of her and how special she was. I am so honored to be her daughter and so grateful for my role as her advocate. My mother was the strongest woman I have ever met. She fought the toughest battle and inspired so many people on her journey back to God. My mother gave so much of herself and I feel she has been a guiding light and an inspiration to all those who knew her. My mother, Maria, has a beautiful soul that will live

on in this world. She will always be with us because she had that kind of presence. She made an everlasting impression on all those who knew her. My mother is my inspiration. May she Rest In Peace. I will cherish every memory we have together for the rest of my life. ♥ "

Maria was always willing to inspire others, and you can see that through the videos found on SPOHNC's website. Maria and her husband Tom participated in SPOHNC's collaboration with Merck, for "Your Cancer Game Plan" – an initiative conveying the importance of nutrition, communication and emotional well-being when faced with a cancer diagnosis.

SPOHNC's Executive Director, Mary Ann Caputo, remembers the day we traveled to Brooklyn to film segments for the video presentation. "When Maria and her husband Tom started to speak about the importance of communication as part of the support one needs during a cancer journey, everyone was so emotionally touched by her spirit. As she told of her journey and how she handled the days she encountered along the way, her story was so heartfelt, that there was not a dry eye in the room. The film crew, Merck executives, and all of those involved in the shoot were so highly affected by her story, that after she finished, there was a half hour break announced, so that everyone could reflect upon Maria's words, which were so very powerful and thought provoking to those who had not experienced a head and neck cancer journey."

SPOHNC's staff, and several survivors from the SPOHNC Syosset, NY Chapter attended Maria's wake and funeral. Stories of her bravery were shared and everyone was deeply touched by her kindness and loving ways. Her family was her greatest source of inner strength and brought her such joy each and every day. She was a devoted grandmother, mother, wife and a friend to all who were part of her life and love. SPOHNC feels this loss very deeply. We will miss Maria and we pray for her family and will be here to support them all during this most difficult time and beyond. We love you Maria, and we will miss you more than you will ever know. You were a very special lady...God bless.

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Survivor News

Sharon Taylor's New Hobby!

SPOHNC hears quite often about some of the joys of survivorship following the diagnosis and treatment of oral, head and neck cancer. Survivors find new purpose in living by doing things they always wanted to do, but "never had the time for." Being a survivor gives a new appreciation for those things, as told by Survivor and SPOHNC Chapter Facilitator, and NSVN Volunteer, Sharon Taylor, MD.

I always thought I would enjoy throwing pottery on a wheel, so when I stopped working, I registered for a beginner's throwing class at the local arts center. There are people who throw a perfect cylinder the first time they



try, but for most of us learning to throw is hard. In time you are able to center a

lump of clay on the wheel, open a hole, pull up the sides, and have a fairly symmetrical piece worth keeping and glazing—success!

There are many aspects of making pots that appeal to me. Learning about glazes, new forms and techniques means there is always something new to stimulate your brain. While I have not found throwing to be meditative as some describe, you are forced to focus, often a goal of meditation, or you may ruin your piece. There is also great personal satisfaction in making something with your hands, be it a loaf of bread or a ceramic pot. When you give such a gift to someone, they know they are special.



photo courtesy of PJ Jordan, NSVN Caregiver Volunteer and amazing photographer

Chapter Chatter from Palm Coast, FL

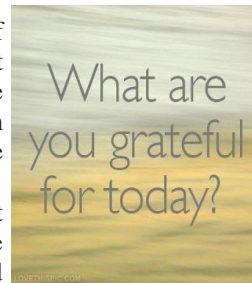
Editors Note: Thank you, Amy and Lewis Beilman, SPOHNC Palm Coast, FL Chapter Facilitators, for always being willing to share the gems from your time with your group. Thank you group attendees, for inspiring others with your thoughts and feelings.

"After all these years I think most of us would agree that our meetings turn out to be informative and worthwhile. The way you all participate makes them so. There were approximately 18 people in attendance, with one new person.

We went around the room and got updates. Then eventually we got to the question "What we're thankful for and what lessons we learned this year?"

As you might suspect, what everyone was most thankful for was family, friends and health. You can change the order but those three things were on the tip of everyone's tongue (expression commonly used unless you've had tongue cancer). Some of the (smart) spouses said they were especially thankful for their spouse

(especially if their spouse was sitting next to them). Some said they were grateful for the group. Some mentioned that they were thankful to be living in this country, during a time when there is so much unrest in the world. Some said they were grateful for each day, to be here, and to give back.



As for lessons learned, Dee said she learned that you have no control over the future...that it's totally out of your control. You have to learn to roll with it...accept it....and move on.....

learning to let things go.....nothing is really guaranteed. So live each day to the fullest.

I'm hoping that despite some of the difficult situations that some of our members had to endure in 2019, we will all give thanks at Thanksgiving for that day. Happy Thanksgiving." Be Well.

~ Love, Amy and Lewis

Survivor News

A Unique Fundraiser for SPOHNC!

SPOHNC was recently contacted by National Survivor Volunteer Network Caregiver Volunteer, and amazing photographer, PJ Jordan. PJ and her husband, Survivor, Mel have been a part of our SPOHNC family since 2009, when PJ connected with SPOHNC to find a match volunteer for herself as a caregiver to Mel. Mel and PJ have had an amazing journey and so they give back (and not just to SPOHNC!) by serving as mentoring volunteers for those who are just beginning their cancer journey. Mel and PJ are incredible!

Now that PJ is retired, Mel and PJ spend lots of time enjoying life – and part of that includes capturing so many beautiful images of nature and the world around them. PJ takes amazing photos which are sometimes featured here in "News from SPOHNC." They also have a great love for music, which is another story – that you already saw on page 8 of this newsletter. These two lovebirds never stop giving and appreciating life to the fullest.



PJ and Mel put together a fundraising campaign for SPOHNC as a different way of "giving back" to the organization that means so much to them. PJ had some of her beautiful cardinal images transferred onto pillows, and posted it on Facebook as a fundraiser. Many people placed orders (including this SPOHNC family in the national office) for these beautiful pillows, with all proceeds being donated to SPOHNC. The limited time offer enabled SPOHNC to be the lucky recipient of a very generous donation of several hundred dollars.

We would like to thank PJ and Mel for this amazing and very thoughtful fundraiser. In addition, to those who purchased pillows, we thank you from the bottom of our hearts, and

we hope you enjoy your pillows, whether giving them as gifts or keeping them for yourselves. SPOHNC is honored to be the beneficiary of this great effort!

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~ Denise L.



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