NEWS FROM S•P•O•H•N•C

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

Physical Therapy From Diagnosis and Beyond

Lisa M. Miller, DPT

From the time of initial cancer diagnosis, there are things you can do to help your quality of life and outlook for each day throughout your cancer treatment plan. Many people have either heard of or experienced physical therapy and rehabilitation. Whether it be after surgery for a knee replacement, after a stroke, or even for common back pain or shoulder pain, physical therapy is frequently prescribed. There are multiple ways that therapy or exercise has the ability to help with a diagnosis of head, neck, or oral cancer. Physical therapy was significantly underutilized in the fight against cancer until now. It is now not only recommended but considered best practice to have regular exercise embedded into the treatment plan for every patient no matter what type of cancer. All members of the multi-disciplinary cancer team should promote physical activity and help their patients adhere to exercise and mobility guidelines. The most expected treatments after a cancer diagnosis include chemotherapy, radiation, immunotherapy, or surgery. Both the cancer itself and any combination of the curative treatments for cancer can take a toll on your body with multiple side effects. The side effects, referred to as toxicities, can include but are not limited to pain, fatigue, balance deficits, difficulty swallowing, peripheral neuropathy, and orthopedic injuries. Changes in posture can greatly affect how the body functions during movement, and these changes can decrease independence in your day to day activities including dressing, bathing, getting in and out of bed, driving, walking, climbing up and down stairs, cleaning, and working. It is important to be aware of what mobility options are available to help fix or manage unavoidable after effects of cancer treatment. Awareness is the most important element when being your own advocate. It is helpful to know there are providers like myself who specialize in helping to regain and maintain your functional independence, movement, and quality of life no matter what stage of your treatment plan you are in. In my current practice, I work with a multidisciplinary rehab group which includes physical therapy, speech pathology, and lymphedema specialists. Our rehabilitation group provides a well-rounded approach and unique treatment plan for each individual patient who is undergoing treatment for head, neck, or oral cancer and the patients who have previously undergone treatment needing further rehabilitation. Whether the individual is newly diagnosed or has been out of treatment for several years, there are many areas I focus on from a physical therapist perspective.

Exercise is defined as any physical activity of the body that improves or maintains health and wellness. These activities can include aerobic, strength, flexibility, and balance exercises. Physical activity has been shown to reduce side effects both physically and psychologically, to improve cardiovascular endurance, increase metabolic and immune system efficiency, help reduce inflammation, lower health-care costs, and improve quality of life. Typically, I encourage my patients to start small and build up exercises slowly as their endurance builds. It is recommended to build up to 150 minutes of moderate exercise or 75 minutes of vigorous exercise per week. This can easily be broken down to just 30 minutes a day for 5 days of the week.

Have you noticed difficulty with just getting through the day? Does getting dressed or preparing a simple meal feel like running a marathon? This could be due to low endurance and weakness causing fatigue. Fatigue is experienced by up to 90% of patients treated with radiation therapy and up to 80% of those treated with chemotherapy; it may already be present in 40% of patients at time of diagnosis. One of the simplest ways to combat fatigue is by working on your endurance with incorporating a walking program into your daily routine. A walking program doesn't require you to be an athlete, but rather helps slowly increase your endurance and as a result decrease daily fatigue throughout your normal routine. Walking is a safe low impact way to keep up strength both in your muscles as well as your cardiovascular system. In my practice, we strive to discuss a walking program with every patient as close to diagnosis as possible. Having these discussions at the beginning of the treatment plan, we can empower patients to build up endurance and tolerance prior to the start of any cancer treatments. Of course, walking is just one of the many ways to reduce fatigue and improve endurance. A skilled therapist can help you find a safe starting point for reduction of fatigue as well as implement a plan to progress safely without falls or injury.

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Balance can be affected many ways throughout treatment as well. Some people have bad balance even prior to cancer treatment due to decreased activity with weakness and fatigue. Our balance system is made up of multiple things including our vision, strength and sensation in our legs as well as our vestibular system. During chemotherapy, both fatigue and chemotherapy induced peripheral neuropathy can affect your stability and balance. Peripheral neuropathy is damage to the nerve endings in your feet and/or hands that decreases the sensation needed for fine motor coordination and balance. Chemotherapy induced peripheral neuropathy affects approximately one third of people. It can take anywhere from 18 months to 5 years to recover from peripheral neuropathy caused by chemotherapy, but sometimes this decreased sensation can be permanent. What can be done to help recover your stability is balance specific physical therapy. Balance therapy acclimates your body to stabilize with increasing strength and creating awareness of how to maintain your balance.

Posture is another key point I focus on with patients from the very beginning of treatment. No matter what treatment is planned or in process to treat your cancer, you want to work on correcting and maintaining posture. Posture is affected by a combination of things throughout treatment for head, neck, or oral cancer. Whether it be from fatigue with decreased mobility or from post-surgery and radiation treatment, posture is often weakened, and the inevitable downward pull of gravity has shortened muscles and skin pulling you out of alignment because of scar tissue and radiation fibrosis. It is important to work on posture from the start to aid in swallowing, improve breathing, decrease pain, increase range of motion, and aid in good functional mobility. Good or correct posture is positioning the body in alignment where there is no stress on the spine. This position where the spine has no stress is called spine neutral. Spine neutral not only helps to decrease muscle tension that can lead to pain and headaches, but it also can help other structures such as the windpipe and throat to work properly for swallowing and opening the airway to improve oxygenation. Postural alignment is also beneficial for improving range of motion for both the neck and shoulders. This can help with function, checking your blind spot, scanning the room, as well as reaching things over head, behind your back, and out to the side with efficiency. Making these movements more efficient and normal will greatly help with decreasing pain. There are specific muscles that work to help maintain your posture. These muscles can be evaluated and pinpointed with exercises to help you obtain and maintain good posture throughout the day.

Stretching and manual therapy is another method used with exercise during rehab to help correct posture, increase range of motion, return functional movement, decrease pain, and decrease tissue restriction from radiation fibrosis. Radiation fibrosis is residual damage caused by radiation. Radiation therapy side effects are varied based on the strength and the number of treatments received. However, 10% of patients who receive radiation to soft tissue of the neck end up with radiation fibrosis leading to pain or discomfort with restrictions of motion. This radiation fibrosis coupled with scar tissue from surgery can cause significant tightness and discomfort. Tightness, pain and neck spasms are patient-reported experiences that can be evaluated by a cancer rehab specialist using established quality of life assessment tools. The good news is there are stretching

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and skilled massage techniques that can reduce the pain or discomfort. One of the first things I work on with my patients is the ability to lay flat with knees slightly bent to protect the lower back. This is sometimes more difficult than it sounds after significant surgery and radiation. Muscles in the front and sides of the neck can get very tight all the way into the chest area causing it to be uncomfortable to lay flat. Sometimes a wedge is needed to accomplish this based on other needs for breathing positionally. The wedge assists with "neutral" spine as we have already discussed its importance. With a vigorous stretching routine, a combination of soft tissue, deep tissue and myofascial release, we can soften the radiation fibrosis, provide decrease in pain or discomfort and improve movement of the neck and shoulders. A skilled therapist can also provide mobilizations of the neck, shoulder, and jaw to assist with pain reduction as well as increasing movement. Often, I teach my patients some of the massage techniques in addition to scar mobilization after surgery to provide self-management for pain reduction and improving movement.

Lymphedema is something that I monitor with my patients, but I am not a lymphedema specialist, so I typically refer to my colleagues in our multidisciplinary team who specialize in lymphedema care. Sheri Puglielli,OT, CLT, who is a lymphedema specialist with Advocate Aurora Healthcare, has provided the following information in regard to lymphedema because it is a common occurrence from a tumor after surgery, chemotherapy, or radiation for head, neck, or oral cancer:

Have you noticed firmness, fullness or tightness under your chin, along your jaw or neck? Do your cheeks or eyelids feel puffy making it difficult to see? Do you have that stuck feeling in the back of your throat when you try to swallow? Does your tongue or lips feel swollen making it difficult to speak and eat? Are you are having a more difficult time breathing? You may be experiencing symptoms of lymphedema. Lymphedema is a condition in which excess lymph fluid collects in tissue spaces due to an overload in the lymphatic transport system. The lymphatic system is part of your circulation and immune system. It consists of vessels which collect and take lymphatic fluid from tissues to the lymph nodes that filter our wastes and toxins. When this fluid remains in the tissue (lymphostatic), it leads to inflammation and a decreased localized immune response. This allows for increased risk of infection in the area. In head and neck cancer, the tumor itself, surgery, radiation and chemotherapy can interfere with drainage of the lymphatic system. The overload of fluid can cause internal or external tissue changes. This can cause increased pressure on nerves, blood vessels and structures creating a feeling of heaviness, tightness and pain. The restriction in tissue mobility from the excess fluid, scar tissue and radiation changes can decrease your head, shoulder, and facial motion. This can then limit your activities of daily living, for example, with having difficulty turning your head while driving or lifting your head back to drink from a cup. Fluid buildup in your neck can make it difficult to wear a button up shirt or tolerate wearing a necklace. Internally, the swelling can affect the inner mouth and throat structures that affect speech, breathing, and swallowing. Swelling can change appearance, therefore affecting self-esteem and involvement in social activities. Early intervention is key, but therapy will help in all stages of lymphedema. How does a certified lymphedema therapist help? An extensive evaluation is completed, which includes reviewing past medical history, cancer treatment history, questions about your past and current activities of daily living performance, social/emotional status/appearance and how the swelling has changed this. The therapist will take measurements of the face and neck, assess head and neck tissue for mobility, firmness, color and temperature, assess the range of motion of neck and shoulders, and facial movement. The therapist will look and gently feel inside the mouth to assess the tongue and cheeks for swelling and restrictions in movement. Treatment includes:

- *Manual lymphatic drainage (MLD) which is a special manual technique that gently stimulates lymphatic node areas and pathways to redirect the lymph fluid to reduce the swelling*
- *Instruction on skin care, infection prevention and lymphedema precautions*
- *Manual techniques to improve scar and radiation tissue mobility for improved lymph drainage and motion*
- *Compression garment recommendations to decrease the refill of the tissue*
- *Sleep positioning education to improve lymph drainage*
- *Instruction on lymphatic drainage exercises to pump the fluid internally and stretches to improve the length and movement of the tissue and muscles*
- *Home program education to help you successfully move to self-management of your lymphedema*

Physical therapy and other rehabilitation services are there for you as a support system to help maintain or recover quality of life. A cancer rehab specialty physical therapist will evaluate and guide you on the path to self-management to give you freedom and independence to move better and decrease pain. I cannot stress enough to you as a patient to advocate for yourself. From the point you are told you have cancer until many years after treatment you can always request therapy and discuss with your doctor if you feel your everyday function is being affected by pain or limited movement. Requesting therapy for guidance throughout your recovery journey is encouraged to ensure safety and a goal driven program to help maximize efficiency for your time spent. Your doctor will let you know if you are cleared to participate with physical therapy or if you have any restrictions for exercise.

Editors Note: Lisa M. Miller, DPT obtained her Doctorate in Physical Therapy from Clarke University located in Dubuque, IA in 2011. Her certifications include LSVT protocol and PWR!! Program for Parkinson's clients, Cancer Rehabilitation Specialist, and Ekso skeleton for retraining gait. She has been working with Advocate Aurora Healthcare in outpatient physical therapy for 8.5 years.

> ***"I enjoy receiving the newsletters and found they have helped so many people who suffer from head and neck issues."***
>
> *~ Theresa L.*

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Head and Neck Cancer News

Study finds blood test accurately tracks HPV-linked head and neck cancer

University of North Carolina at Chapel Hill School of Medicine - An experimental blood test accurately detected HPV-linked head and neck cancer recurrence and confirmed when patients remained cancer-free, according to findings from a study led by University of North Carolina Lineberger Comprehensive Cancer Center researchers.

The findings, published in the *Journal of Clinical Oncology*, were from the largest and most comprehensive study using an experimental blood test to track patients with oropharyngeal cancer linked to human papillomavirus, or HPV.

The researchers reported the test was 99 percent accurate in confirming patients remained cancer-free after treatment compared with other screening methods. For patients who had two HPV-positive blood tests after treatment, the test was 94 percent accurate in detecting cancer recurrence.

“The major utility of this test is it’s going to improve our ability to monitor patients after they complete treatment,” said UNC Lineberger’s Bhisham Chera, MD, associate professor in the UNC School of Medicine Department of Radiation Oncology. “Currently, our methods to assess whether the cancer has recurred are invasive, expensive and not always accurate.”

Infection with certain strains of HPV can cause cervical cancer, genital cancers and cancer of the oropharynx, which is the back of the throat, including the base of the tongue and tonsils.

With the goal to improve cancer tracking, UNC Lineberger researchers designed a test to detect HPV genetic material that dying cancer cells have released in to the blood. Intellectual property for a form of the experimental test was licensed to Naveris Inc.

“We developed a technology that enabled us to distinguish HPV DNA that came from a tumor from HPV that’s simply related to infection,” said UNC Lineberger’s Gaorav Gupta, MD, Ph.D., assistant professor in the UNC School of Medicine Department of Radiation Oncology.

In their latest study, researchers evaluated 115 patients who underwent chemotherapy and radiation treatment for oropharyngeal squamous cell carcinoma linked to HPV16.

Patients were screened for recurrence using PET/CT body scans, chest imaging, and physician evaluations. They received a blood test every six to nine months.

“For this study, we systematically applied our assay to over 1000 patient blood samples obtained from the clinical study,” said Sunil Kumar, Ph.D. postdoctoral fellow at UNC Lineberger.

Initially, 28 patients had a positive HPV blood test, indicating a possible recurrence, but only 15 of those patients were diagnosed with recurrence based on a biopsy.

When 28 patients who initially received a positive test result underwent a second blood test, only 16 were found to be HPV positive.

That indicated to researchers that two consecutive positive blood tests indicated a recurrence, and led to a sensitivity level for the test of 94 percent.

“In this study, we had accumulated enough follow-up data to see who was going to develop recurrence and who wasn’t,” Gupta said. “That allowed us to determine that the test performs best if you look at two consecutively confirmed blood tests.”

Meanwhile, for 87 patients who had negative HPV blood tests in all their screening sessions, none developed recurrence.

Chera said the experimental test could improve follow-up screening for this type of head and neck cancer, which can involve imaging every six months or annually, and inserting a scope into the nose and down the throat every two to three months in the first two years after a person completes treatment.

“With this new technology, it offers a noninvasive way to accurately monitor patients for cancer recurrence,” Chera said. “In the long run, blood-based surveillance could be more effective, and possibly help us to detect cancer sooner.”

April is Oral, Head and Neck Cancer Awareness Month

Show Your Support

Raise Awareness

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or call
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When you shop on AmazonSmile, the AmazonSmile Foundation will donate 0.5% of the purchase price of eligible products to the charitable organization of your choice.

Time for Sharing...*You Are Not Alone*

My name is Jeff Danzik. I am a throat cancer survivor. I am also a licensed clinical social worker and I work as a psychotherapist in private practice. I work with many individuals who have experienced grief and trauma in their lives. Prior to my own cancer diagnosis, I had little experience dealing with cancer and never really considered that experiencing cancer can be a traumatic event.

On August 30, 2017, I received my official diagnosis—P-16, HPV positive, squamous cell carcinoma of my epiglottis with right lymph node involvement. Several small tumors had grown where my tongue met my throat, and the cancer had spread to a few lymph nodes on the right side of my neck. I was fifty-four years old and in excellent health. There was no logical reason for me to have throat cancer, and yet there it was.

My treatment included six rounds of day long chemotherapy treatments, thirty-three radiation treatments to my neck, two months of two- to three-hour per day hydration sessions, five months of using a feeding tube exclusively to eat, and a hospital stay when my body just got too tired. Throughout most of my treatment I felt sick. I could not eat. I lost thirty-five pounds. I slept as much as possible, and I could not work due to experiencing a number of side effects. I completed my treatment on November 30, 2017 and so far, I remain cancer free with only minimal long-term side effects.

Cancer is scary. I found every phase of the cancer process—diagnosis, preparation for treatment, treatment, and recovery—physically and psychologically stressful. The medical community primarily focuses on the diagnoses, physical impact, and treatment of this disease. They typically don't deal with the psychological aspects of cancer. Of the dozens of medical professionals I saw during my cancer process, it was extremely rare for any to ask how I was doing emotionally. Issues such as grief, depression, anxiety, fear, and trauma were rarely, if ever, discussed. Yet, there is not a cancer survivor whom I have spoken with who has not experienced or continues to experience some or all of these issues.

Psychological distress may also be experienced by significant others and family members; it is not limited to only the patient. Watching someone you love deal with cancer can be a traumatic experience. Emotions such as fear, depression, helplessness, and anger may be experienced by care givers and/or family members, and they may need help and support as well.

For me, dealing with the psychological impact of my cancer and treatment was as challenging, if not more challenging, than dealing with the physical impact. Just as the physical effects of cancer and treatment can be complex and unpredictable so too can the psychological effects. It is also possible that psychological healing can take longer than physical healing, and it is harder to measure. Physical wounds are visible, psychological wounds are not.

Feeling angry, depressed, anxious, and fearful are normal reactions to cancer. Dealing with cancer is a traumatic life event, and the impact does not necessarily go away when treatment ends. We learn to live with a new normal. Our identity changes. Goals and priorities and our perceived purpose in life will likely change. Even our belief in whatever higher power we ascribe to (or don't ascribe to) will be called into question.

How the trauma of cancer and treatment impacts you and those around you will depend on several things: your basic personality type, how you cope with stress, and the support system you have and create. The type and location of your cancer, the prognosis, the duration and type of treatment, the severity of side effects, the outcome of your treatment, the lifestyle changes that may be necessary, and your physical health— will all impact how you deal with the cancer process both physically and psychologically.

We still seem to think about cancer and treatment as primarily causing physical distress. However, it is likely to cause some psychological distress as well. Sometimes the psychological impact does not surface until after treatment has ended. This is not uncommon. It is like the mind was so busy just trying to survive during treatment that it didn't have time to process everything that happened until after the fact. In my case, it was about five months after treatment ended that I began to experience concerning levels of depression, fear, and anxiety.

After treatment, my last hospitalization, and my port and feeding tube removal, I wasn't sure how to process everything that had happened. Physically, I was finally feeling better and experiencing increased energy. The pain in my throat subsided. My taste buds, though altered, were returning. I had only minor physical side effects that continued after my treatment. This included an altered sense of taste, dry mouth, some swelling in my neck, and some minor difficulty swallowing due to scar tissue in my throat, the result of the radiation.

Though I was healing physically, and there was no longer any detectable cancer in my body, I seemed to feel worse emotionally. I am not sure what I expected when my treatment ended, but I was surprised by my emotional state. I was angry, could not stop thinking about recurrence and death, felt anxious much of the time, and started having nightmares. Instead of feeling hopeful for my future, I was scared and pessimistic.

The issues I was experiencing were common symptoms of trauma. Of all the dozens of medical professionals I saw during my cancer process, the word trauma was never mentioned. Of the numerous potential side effects of treatment that were discussed or listed in literature I received or forms I had to sign, there was nothing said or written about the potential psychological impact of cancer and treatment.

When my treatment ended and my body had mostly recovered, I felt very alone. Most people who knew me figured that I was fine given that I looked and felt better physically, and I no longer had cancer. The outpouring of support diminished as people went on with their lives. I never assigned any malice to this. This was understandable. Emotional scars cannot be seen, and unless someone has been through a trauma or worked closely with people who have, it is extremely difficult to understand the impact. This is further confused by the fact that often

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the full impact of a traumatic event takes time to surface. Here I was, five months post treatment, cancer free, and feeling emotionally distraught.

I was hard on myself. I told myself that I should have been feeling happy and thankful. I was alive, and I was physically healthy again. I told myself my experience was not that bad, and I shouldn't have any issues as a result. Instead of joy and gratitude, I was full of fear and guilt. How do I explain to others that I feel guilty about surviving cancer? How do I justify my existence when there are so many good people who won't survive cancer and so many bad people who will never get it? Why did I survive while others did not and would not? None of this made any sense to me.

Why was I even writing about my experience? Who was I to presume that my story was even worth telling? I had cancer. I got treatment. I got better. What was the big deal? I was just spoiled and needed to get over myself.

I had this standard in my head about how I should feel post cancer. Like in the movies, the world was supposed to be brighter, food was supposed to taste better, the birds would sing more, everyday would be sun and roses, and…it wasn't so. In many ways I was more confused, more frustrated, and more disillusioned. The cancer process was like someone took me out of my world, turned it inside out, shook it around a bit, reorganized and reshaped it, and then put me back in it without a map.

I still got angry when stuck in traffic. I still became annoyed and impatient with others. I still complained. These were things I was never supposed to do again because I had a second chance, a new lease on life. I was supposed to come out of my cancer process as a new and enlightened person, having unlimited compassion for others and an appreciation for life that others would see and admire. This is how I wanted to be, hoped to be, and strived to be.

I have had only brief glimpses of these virtues. There are moments where I experience what true appreciation and presence feel like—a genuine connection to the universe. Then, I try to grasp at it to make it last, and it slips away—and I am reminded that I am only human.

Given some time and distance from my cancer and treatment, as well as professional and peer support, my emotional state has improved. The nightmares have become rarer, and I don't feel hopeless. My anger and anxiety have diminished. I can think about my future now whereas before I had trouble thinking past the next day. I also accept that I will always have some level of fear about cancer, something I never even thought about before.

One of the difficult things about trauma is that there is no way to predict how long it may or may not impact someone. It can be triggered at any time, often unpredictably. There can be good days and bad days or even good moments and bad moments. However, the symptoms of trauma can become more manageable and less intense. We can learn to not let it interfere with living life.

Finding professionals to talk with was invaluable for me. During treatment and into recovery, I met weekly with an oncology social worker, had regular meetings with the nurse navigator, started attending a support group for head and neck cancer survivors, and found a good therapist. You will have a medical team, why not have a psychological team as well? Cancer is an assault on the body and on the mind. Caring for oneself emotionally during treatment and recovery can be as important as caring for oneself physically.

Cancer and treatment changed me physically and psychologically. Physically, I deal with the loss of my thyroid function, changes in my ability to taste food, fatigue, swelling in my neck, and hearing loss. Emotionally, I find that there are still things that will trigger me, causing me to experience fear and anxiety. At times it is hard for me to talk about or even think about my experience. My tolerance for dealing with stressful situations is sometimes less than it used to be. I find that I need more rest than before treatment. This is part of my new reality—my new normal— and I find this a more than acceptable trade off for still being alive.

Throughout the cancer process there can be many difficult and disturbing thoughts and feelings. There is no single way to deal with these. Though a normal part of dealing with cancer, these thoughts and feelings may still cause issues and help may be needed to deal with them. It is also likely the medical community will barely address the psychological impact or not address it at all. If you are in distress, there are therapists, support groups, and survivors willing to help. Being patient and taking care of yourself emotionally as well as physically are important factors for recovery. You can learn new coping skills and process through your emotions. Just as healing physically from cancer and treatment takes time, emotional healing takes time. You are not alone.

~ Jeff Danzik
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TOGETHER WE HEAL

Want to help someone who is just beginning their cancer journey?

Join *our*
National Survivor
Volunteer Network

Start *a*
SPOHNC Chapter
Support Group

Contact *SPOHNC to find out*
how you can
Help Make a Difference!

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

A Marvelous March Menu from "Eat Well Stay Nourished A Recipe and Resource Guide For Coping With Eating Challenges"

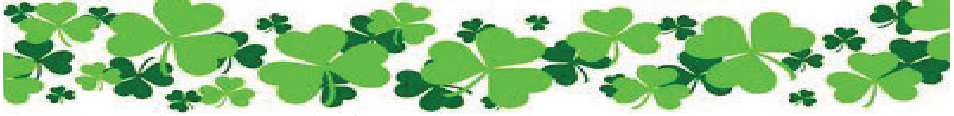
Compiled and Edited by Nancy E. Leupold, Founder, in memoriam

Potato Leek Soup (from Volume One)

3 Tbsp. butter
1 bunch leeks
2 medium potatoes, peeled and diced
3 c. chicken broth
½ pt. light cream
Salt and pepper to taste
Fresh parsley or chives, minced

Cut off most of the green tops of the leeks. Split the leeks lengthwise almost through and wash thoroughly under cold running water to remove all sand. Slice thinly. Melt butter in heavy saucepan and add leeks. Summer slowly over low heat until transparent. Add potatoes and chicken broth; simmer about ½ hour or until potatoes are soft. Puree in a blender or food mill and return to heat. Stir in cream and season with salt and pepper. Serve hot or cold with sprinkled fresh herbs. Yields 5 (8 oz) servings. *229 calories per serving*.

~ Mort G., NJ



Noodle Pudding (Kugel) (from Volume Two)

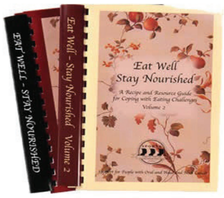
1 (12 to 16 oz.) pkg. broad egg noodles
3 to 4 eggs, depending upon size of eggs
1 c. sugar
1 large container cottage cheese
1 large container sour cream
Lots of cinnamon
Butter to use as topping

Prepare the broad noodles according to box directions. Beat the eggs, adding sugar a little at a time. Add cottage cheese, sour cream and cinnamon, mixing thoroughly. Add cooked egg noodles to the mixture, stirring so that all ingredients are blended together. Pour into 9 x 13 pan that has been sprayed with a butter flavored spray. Dot with butter or margarine. Bake for about 35 to 40 minutes at 350 degrees until top is slightly browned. Serve warm. Serves 12. *353 calories per serving*.
NOTE: A low-fat version can be made by substituting low fat cottage cheese and low fat sour cream.

~ Amy B., FL

Eat Well Stay Nourished A Recipe and Resource Guide for Coping With Eating Challenges

compiled by
Nancy E. Leupold, Founder
in memoriam



SPOHNC is offering a great bargain for its Eat Well Stay Nourished Vol. One and Vol. Two Cookbooks… Buy One Get One (BOGO).

BUY ONE GET ONE

Both cookbooks help to prepare recipes for those who are coping with eating challenges.

For a limited time SPOHNC is offering a discounted price of $25.00 (Includes shipping & handling) for both Volume One and Volume Two… a $15.00 savings.

Purchase a gift set for your loved one or friend who you know is struggling with their daily meal plans for nutrition.

Go to spohnc.org to order, or call SPOHNC today at 1-800-377-0928

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Chapter News

SPOHNC is having a growth spurt! Over the last few months, SPOHNC has had the pleasure of welcoming a few new Chapters, who are ready to support patients, survivors and family members who have been affected by the diagnosis and treatment of oral, head and neck cancer.

SPOHNC has more than 100 Chapter Support Groups across the United States. Our SPOHNC Chapter Support Groups are facilitated by healthcare professionals, survivors and caregivers as well. Group attendees tell SPOHNC that there is nothing like the camaraderie shared among those who attend a SPOHNC support group. A support group is like a family, and can provide you with insight and hope along your cancer journey.

Welcome to our new SPOHNC Chapters located in Bay Shore, New York and Southampton, New York. They join our Long Island groups which include Syosset, Stony Brook and New Hyde Park.

Welcome also to Danville, Pennsylvania. They join our groups in Pennsylvania which include Dunmore, Hershey, Lancaster, Lebanon, Philadelphia, University of Pennsylvania and York.

If you are interested in finding out more about the day, time and location of a support group near you, contact SPOHNC at 1-800-377-0928. To find out more about how to start a support group, contact us at info@spohnc.org. If there is not a group nearby, SPOHNC has additional programs of support to help you along your cancer journey. Reach out to SPOHNC – we're here for you.

"A SPOHNC Chapter is much more than a place to meet because you have been unfortunate enough to contract a disease. It is a place to find comfort and encouragement not only for the patient but for the caregiver, family and friends. There is healing in numbers as well as healing in opening up and voicing your fears and concerns to others who are listening with open hearts and minds, others who have been there and know exactly what you are going through."

~ Charles Bartlett, SPOHNC Minneapolis, MN Chapter Facilitator

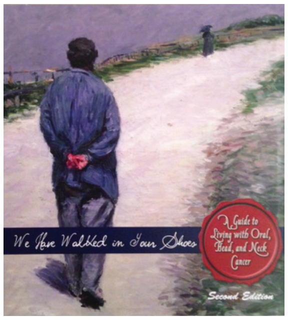
Oh, the Places We've Been!!

Welcome to a new feature in "News from SPOHNC." Have you been on a journey recently that you'd like to share with our readers? We can help! Send us your photos and a short paragraph about your special trip, so we can share the great news in an upcoming issue. Let's travel together!

This month's journey was taken by oral cancer survivor, Chris and caregiver, Connie Lunt. Chris and Connie are also volunteers for SPOHNC's National Survivor Volunteer Network. Here's what Connie shared with SPOHNC…

Chris and I just arrived back from a "trip of a lifetime!" Antarctica! The adventure began in Buenos Aries and included The Falkland Islands, South Georgia, Antarctica and the famous Drake Passage.This adventure has been a backlist item for over 10 years for us. We experienced so much wildlife! Penguins, Seals, Birds, etc. We really are "Living the Dream!"

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

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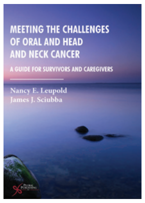

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HEAD AND NECK CANCER NEWS

Plant-derived SVC112 hits cancer stem cells, leaves healthy cells alone

Study shows drug SVC112 stops production of proteins that cancer stem cells need to survive and grow.

January 8, 2020 - University of Colorado Anschutz Medical Campus - The red, tube-shaped flowers of the firecracker bush (Bouvardia ternifolia), native to Mexico and the American Southwest, attract hummingbirds. The bush also provides the chemical bouvardin, which the lab of University of Colorado Cancer Center and CU Boulder researcher, Tin Tin Su, PhD, and others have shown to slow a cancer's ability to make proteins that tell cancer cells to grow and spread. Now a paper based on nearly half a decade of work, published in the journal *Cancer Research*, shows that the molecule SVC112, based on bouvardin and synthesized by Su's Colorado-based pharmaceutical startup, SuviCa, Inc. acts specifically against head and neck cancer stem cells (CSCs), resulting in better tumor control with less toxicity to healthy cells than existing, FDA-approved protein synthesis inhibitors. The group hopes these promising preclinical results will lay the groundwork for human clinical trials of SVC112 in head and neck cancer patients.

"Proteins are the keys to initiating genetic programs in the cells to tell them 'Now you grow, now you stay put, now you metastasize.' and those proteins are called transcription factors," says paper co-senior author, Antonio Jimeno, MD, PhD, director of the Head and Neck Cancer Clinical Research Program and co-leader of the Developmental Therapeutics Program at CU Cancer Center, member of the Gates Center for Regenerative Medicine, and the Daniel and Janet Mordecai Endowed Chair for Cancer Stem Cell Research at the CU School of Medicine.

Cancer stem cell (CSCs) are a subpopulation of cancer cells that, like healthy stem cells, act as factories, manufacturing cells that make up the bulk of a cancer's tissue. Unfortunately, CSCs often resist treatments like radiation and chemotherapy, and can survive to restart tumor growth once treatment ends.

"Many groups have linked the production of transcription factors to the survival and growth of cancer stem cells, but inhibitors have just been too toxic -- they come with too many side effects. Definitely our studies suggest that this drug could be an advantage over existing drugs. It inhibits protein synthesis in a way that no other drug does and that's why we're excited," says Su, who is also co-leader of the CU Cancer Center Molecular and Cellular Oncology Program.

Importantly, the group's work showed that SVC112 acts specifically against proteins like Myc and Sox2 needed by cancer stem cells, while leaving healthy cells relatively unharmed. They did this by comparing the effects of the drug in "matched pairs" of cancer cells and healthy cells grown from samples graciously donated by five head and neck cancer patients in Colorado. For further comparison, the group did the same experiments with the FDA-approved protein synthesis inhibitor known as omacetaxine mepesuccinate (also called homoharringtonin, or HHT).

"Having cancer cells along with matched non-cancer cells from the same patient is pretty unique. When we tested these matched pairs with SVC112 and with HHT, what we saw is the approved drug eliminated both cancer and normal cells, whereas SVC112 had selectivity -- it affected cancer cells but not healthy cells -- so theoretically the effects on the normal tissue will be less," Su says. In fact, healthy cells were between 3.8 and 5.6 times less sensitive to SVC112 than were cancer cells (healthy cells and cancer cells were equally sensitive to the FDA-approved drug HHT).

The next step was using SVC112 to treat head and neck tumors grown in mouse models from samples of human tumors. Earlier work had shown that SVC112 sensitized previously radiation-resistant CSCs to radiation treatment, and so the group tested SVC112 and radiation alone and in combination.

"What we saw is that only when you decrease the population of cancer stem cells to under 1 percent of the total makeup of a tumor did the tumor shrink," Jimeno says. "It's like cancer stem cells are in the control tower, directing the growth of the tumor. If you impair enough of these directors, other cancer cells don't know what to do and cancer growth slows down or stops."

Ongoing work continues in two major directions, with Su's team continuing to propel the drug toward the clinic and Jimeno's team working to understand of the basic biology driving the drug's action, how to best combine it with other treatments such as radiation or immunotherapy, and its potential uses in other cancer types.

"This is the first report of the drug, from the drug's chemical structure, its basic effects on commercial cell lines, to its mechanism of action with patient-derived cell lines and more complex action on CSCs, all the way to animal models from patient samples," Jimeno says.

Early drug development undertaken outside the funding structure of established pharmaceutical sponsors often requires contributions from many sources, and the current project is no exception, receiving support from subcontracts to SuviCa's Small Business Innovation Research (SBIR) award, a National Institutes of Health grant to the Su lab, pilot funding from the CU Cancer Center, and philanthropy support from the Gates Center and the CU School of Medicine.

"We are so grateful for the belief from all these organizations and individuals, and especially to our patients, whose courage has been essential in making the models we need to test this new drug," says Jimeno.

Proposals are already underway to take the next important step: Testing SVC112 in an early human clinical trial.

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HEAD AND NECK CANCER NEWS

Botanical drug is shown to help patients with head and neck cancers

University of California, Los Angeles - In a UCLA-led phase I clinical trial, a new plant-based drug called APG-157 showed signs of helping patients fight oral and oropharyngeal cancers. These cancers are located in the head and the neck.

APG-157 is made up of multiple compounds produced by plants, including curcumin. UCLA Jonsson Comprehensive Cancer Center researchers found that treatment with this botanical drug resulted in high concentrations of curcumin and its byproducts circulating in the blood and absorbed by tumor tissues within three hours after being taken orally.

APG-157 reduced the concentration of cytokines—proteins involved in inflammation—in the saliva when administered to cancer patients. The therapy also reduced the relative abundance of Bacteroides species, a group of gram-negative bacteria. Gram negative refers to a group of dangerous bacteria that have an outer layer which hides them from the immune system. The relative abundance of gram-negative bacteria compared to the presence of other types of bacteria is correlated with oral cancer.

APG-157 also resulted in the expression of genes that are associated with attracting immune system T cells to the tumor area. This therapy could have a beneficial effect when used in combination with immunotherapy drugs that help immune system T cells recognize and kill tumors.

The treatment did not have any adverse effects on the study's participants.

Cancers of the head and neck account for 4% of all cancers. About 650,000 new cases are reported each year around the world. People with advanced head and neck cancers have a low survival rate and current treatment options such as surgery, radiation and chemotherapy can have adverse effects. Therefore, more effective and less toxic therapies are needed to help improve the quality of life and outcome for those with these cancers.

APG-157 is a botanical drug developed under the FDA's Botanical Drug Guidance, which includes requirements for production of plant-based therapies that are marketed as prescription medications. The drug is made up of botanical compounds including curcumin from the Curcuma longa plant, which is commonly referred to as turmeric and is a member of the ginger family.

Curcumin is one of the medicinally active or therapeutic molecules that has been tested as a possible treatment to help fight multiple cancers because it is an antioxidant that reduces swelling and inflammation. However, there is poor absorption into the bloodstream when curcumin is taken orally. In this study, UCLA researchers found that when APG-157 is taken through oral mucosal absorption, patients have high levels of curcumin circulating in their blood and absorbed by cancer tissues.

UCLA researchers conducted the study of APG-157 comparing 12 people who had oral and oropharyngeal cancer with a control group of 13 people who did not have cancer. The reason both the people with cancer and without cancer were part of the study was to show that the drug was not toxic to either people with cancer or those without cancer.

The medication was given each hour for three hours and was delivered as a lozenge that slowly dissolved in the mouth. Blood and saliva samples were collected beforehand—each of the three hours the medication was administered—and 24 hours after the last dosage. The medication was given to 12 people (some who had cancer and some who did not) and a placebo was given to 13 people. Blood and electrocardiogram tests did not show increased toxicity in the people who took the active medication in comparison with the people who took the placebo, regardless of whether they had cancer or not.

March

Racing clouds and whistling winds,
Coats flapping in the breeze,
Bright kites circling in the skies,
The dance of swaying trees,
The cheerful sight of crocuses,
The first sweet breath of spring –
Just part of all the many moods
The month of March can bring.

For the cancer patients who took the medication, there was a decrease in Bacteroides and an increase in T cells in the tumor tissue as compared to cancer patients who took the placebo. Neither the subjects nor the investigators knew whether the drug or a placebo was given when reviewing the blood and saliva test results of the blinded study.

APG-157 is a botanical drug that has low toxicity. It works effectively to reduce inflammation that contributes to the growth of cancer cells. It also attracts T cells to the tumor micro-environment. When used in combination with immunotherapy drugs, APG-157 might have the ability to make the immune system more effective in attacking head and neck cancers. With potential to inhibit the growth of Bacteroides species, APG-157 could also improve cancer therapy through oral microbial changes.

April is Oral, Head and Neck Cancer Awareness Month

*April is almost here.
Are you, or your support
group, doing something
to raise awareness of oral,
head and neck cancer?
If you'd like to tell SPOHNC
about it, send us some details
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*SPOHNC is working hard
to raise awareness,
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across the country
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> *"Coming to the meetings gives me a sense of accomplishment – to see how all of my friends are doing and making progress"*
>
> *~ Ray G.*

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