

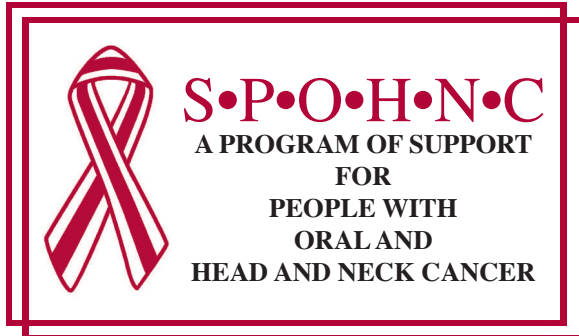
# NEWS FROM S•P•O•H•N•C



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

MARCH 2016



## Physical Therapy For Head and Neck Cancer Patients

Leslie Waltke, PT, DPT

Early one morning Sandy came in for her appointment at the local cancer rehabilitation center. The clinic was bustling with people with lung cancer, brain cancer and breast cancer. Like the other patients, she did her prescribed leg strength exercises, spent time on the treadmill and worked on her given balance exercises. When finished, it was time to see the physical therapist to undergo soft tissue mobilization to the skin where she had been radiated.



Physical therapists treating pain, weakness, fatigue, fibrosis and issues related to chemotherapy-related neuropathy are common in a cancer rehabilitation center. What's unique in this scenario though, is Sandy. Sandy too is being treated for fatigue, weakness and walking difficulty because of her neuropathy. However, there is a difference between her and the other cancer patients in the clinic. Sandy has oral cancer.

Physical therapists are doctoral trained, licensed healthcare professionals that specialize in assessing and treating problems related to the body's musculoskeletal (muscles and bones), cardiopulmonary (heart and lungs) and neurological systems (brain and nerves). Whether it's after a significant surgery, illness, injury, accident or cancer, physical therapists use treatment techniques to reduce pain, improve mobility, restore function, reduce disability and teach people to live better and healthier. Just like after a major knee surgery or stroke, people with cancer will typically do better if they have a physical therapist on their care team.

### Why add physical therapy for people with oral and head and neck cancer surgery?

The goal of surgery for oral and head and neck cancers is to eliminate or better control the disease in the area. Surgeons are very careful to preserve nerves and structures in the affected region. Sometimes though, the necessary removal of the cancer may lead to temporary or permanent changes to nearby nerves, muscles and structures. These changes may cause difficulties with swallowing, breathing and speaking. If so, patients are referred to a speech and language pathologist and registered dietician. This critical post-operative rehabilitation is the first step in relearning and regaining these core essentials of life. Studies also suggest that about 50% of people undergoing oral, head and neck surgery may also have some amount of post-operative shoulder trouble, including pain and weakness. The pain and weakness may be a part of the recovery process, but sometimes it may result from damage or trauma to the accessory nerve (cranial nerve eleven). The accessory nerve innervates and controls the trapezius muscle (in the upper back and neck) and the sternocleidomastoid muscle (on the side of the neck). A physical therapist will assess the current nerve and muscle functions and develop strength and range of motion programs to assist in nerve recovery, strengthen the muscles to their maximum potential and ensure the neck and shoulder joints stay healthy and mobile. Even in the case of permanent muscle or nerve loss, physical therapy can help reduce or eliminate pain and strengthen the surrounding muscles and joints to ensure restoration of maximum movement, function and comfort.

### So if Sandy has an oral cancer, why does the physical therapist have her on the treadmill and strengthening her legs?

The National Comprehensive Cancer Network states that fatigue is both the most common as well as the most distressing complaint of people undergoing treatment for cancer. Even though cancer-related fatigue is so common with cancer treatment, it really isn't all that well understood. We know things like anemia (low red blood cells), infections, changes in heart and thyroid function, and altered sleep and nutrition can *contribute* to fatigue. But even when all of those issues are eliminated, most people will still suffer some level of fatigue when undergoing chemotherapy and radiation. Ultimately though, on a physiological level we don't know exactly why fatigue happens and what causes it.

In healthcare, large studies called randomized controlled clinical trials search for new treatment strategies, and give us a good indication of which methods work the best. Randomized trials have studied the use of exercise as treatment for cancer-related fatigue and overwhelmingly tell it is the best way to combat this tiredness. Not only have the studies proven that exercise is safe, but also that it is essential and beneficial to people before, during and after chemotherapy and radiation. These studies don't tell us *why* exercise helps minimize fatigue, only that it does. Many theories

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**Chris Traxler**

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**IN THIS ISSUE**

Time For Sharing.....4  
 National Nutrition Month.....6  
 Head & Neck Cancer News.....7,8, 10  
 In Memorium.....9  
 Chapters of SPOHNC.....11

continued from page 1

exist on how exercise may reduce chemotherapy and radiation-related fatigue. These theories include helping the body better manage insulin, creating a stronger heart and more efficient lungs, generating the growth of more red blood cells, helping maintain muscle mass, improving immunity and even helping the body better regulate cytokines, the signaling molecules that help our cells communicate with each other.

The bottom line is that exercise helps eliminate and reduce cancer-related fatigue. It is so important that the American Cancer Society now recommends 150 minutes or more of exercise a week for cancer patients during treatment as well as for cancer survivors. About half of those minutes should be in a medium range intensity, a level causing the need to breathe a bit heavier. For people just starting out or feeling overwhelmed, the research tells us that any movement or exercise is better than none. Taking a 3-minute slow walk may be a great starting point for someone experiencing extreme fatigue. For people undergoing chemotherapy and radiation treatment, physical therapists will develop and tailor aerobic exercise programs, such as walking and bicycling, to allow them to continue moving and to keep their lungs and hearts working well. Therapists help patients understand when and how much to push and when to stop or slow down. In addition, to combat the muscle loss that often accompanies treatment, specific strength exercises like squats and leg lifts, will be prescribed to keep the body's large muscle groups (quadriceps, hamstrings and gluteals) strong. These beneficial effects of exercise are not limited to a single type of chemotherapy or a single kind of cancer. Whether it is oral cancer like Sandy is experiencing, colon cancer or another type of cancer, patients should be engaging in aerobic and strength exercise.

**And Sandy's balance exercises?**

Numbness, burning and tingling in the hands and feet, also called neuropathy, are a frequent side effect of some chemotherapy drugs. An example is Cisplatin, a drug commonly used to treat head and neck cancers. Unfortunately, there is no documented method to prevent neuropathies from occurring. While exercise and rehabilitation will not have a direct effect on the amount of numbness or tingling, any associated hand weakness or dexterity problems can be enhanced, and any difficulty with walking, leg weakness, or problems with balancing or climbing stairs may be greatly improved. This will go a long way in boosting the quality of life for those living with short and long term neuropathy.

**Physical therapy and cancer survivorship**

In addition to fatigue, radiation may also cause skin changes that can lead to physical and functional problems. Radiation has both "acute" or immediate effects, as well "late" effects that can present months or years later. A physical therapist watches for and develop programs to minimize both these acute and delayed symptoms. During radiation, the skin in the targeted area may become very tender (radiation oncologists call this desquamation) which may lead to pain and movement difficulties. While providing treatment to keep the heart, lungs and muscles strong, physical therapists will also help in this acute phase by providing adaptations to activity and exercise often needed in the last weeks and days of radiation due to the desquamation.

continued on page 3

continued from page 2

Being well known for its late effects on skin, underlying soft tissues and muscle, I like to call radiation “the gift that keeps on giving.” Like scar tissue development that may happen many months after surgery, some skin and muscle in the radiation field may develop tightness, firmness or fibrosis several months to several years after the conclusion of the radiation. This can lead to pain and tightness in the area and movement difficulties and atrophy in the surrounding muscles and joints. Though nothing can completely reverse these changes at a cellular level, a physical therapist can mobilize, soften and lengthen the affected skin and tissues, allowing them to move better and be less painful. Strengthening the muscles in and around the radiation field and restoring normal joint mobility is also critically important to a full, pain free recovery.

Another potential long term impact of cancer treatment is lymphedema. Lymphedema is swelling that may develop in the area of the body treated with radiation or surgery. In the case of oral, head and neck cancers, this usually includes the face, chin or neck. The lymphatic system is found right underneath the skin and encompasses nearly the entire body. It is a series of vessels and nodes that have several roles, one of which is to collect fluid and waste products from the tissue under the skin, clean it and return it back to the general circulatory system in the chest. There are about 600 lymph nodes in the body and they also have multiple functions. One primary job of the lymph nodes is to filter out unwanted things like waste products, bacteria, broken cells and even cancer cells from the collected fluid as it makes its way back to the heart. (This is a reason why many oncology surgeries include removing and looking at lymph nodes from near the tumor to see if they contain cancer cells to help stage the disease.) If lymphatic vessels or lymph nodes become damaged by radiation or surgery they may have trouble removing fluid from that particular area and swelling, called lymphedema, may result.

For people that develop facial or neck lymphedema, treatments may include manual edema mobilization, where a therapist uses their hands to decrease the effects of any scar tissue and to stimulate the remaining lymphatics in the area as well as the nearby circulatory system to reduce the swelling. Exercise too is a great treatment for

lymphedema. The muscle pumping action of strength exercises and the stimulation of the lymphatic system by increasing breathing and heart rate also decrease lymphedema.

Another area of cancer survivorship physical therapists can help people is with body weight. Studies show that being overweight or underweight after cancer treatment has the potential to decrease life expectancy in cancer survivors. Physical therapists can assist people who are overweight in developing safe and gentle exercise program that with along with diet have been proven to help lower body mass index.

If you are having trouble with either gaining weight or maintaining weight, rehabilitation can assist here as well. When people have become very thin with treatment, exercise assists in building muscle mass and helping the body regenerate itself. Once people get stronger and have less pain, appetites usually improve and they are better able to stand to make meals and get out into the community.

### **So you really want me to go to physical therapy when all I feel like doing is crawling into bed?**

There is a subtle underlying assumption in oncology that once you’re diagnosed with cancer it’s “normal” to be miserable. Even well-meaning healthcare providers and family members can inadvertently promote this perception by encouraging patients not to move and to “take it easy.” We’ve learned over the years though, that rest isn’t good medicine and sitting on the couch makes people weaker, not stronger.

Cancer treatment can be downright brutal. And treatment for oral and head and neck cancers can be exceptionally brutal. I’ve been treating cancer patients for over 20 years, so I am very familiar with the looks I get when I ask someone with debilitating fatigue to get on the treadmill or ask someone with excruciating pain in their upper back or neck to lift their arm over their head. Just like rehab after a rotator cuff repair, the first visit after surgery or treatment can be challenging. Happily, and most likely, at the conclusion of the appointment patients will be moving more freely and with less pain. Most important though, they will have just set off upon the path to a full recovery.

The final take home story is that rehabilitation helps reduce the fatigue,

weakness, pain and loss of function associated with cancer surgery, chemotherapy and radiation and helps people regain the life they love. What’s even more wonderful is that rehabilitative treatment is low risk, low cost and with a high benefit payout. Cancer rehabilitation is evidence based, insurance reimbursed medical care that all patients with cancer deserve access to. That’s why my rehabilitation colleagues and I are working hard to get people with oral and head and neck cancers, along with all cancer patients and survivors, better access to rehabilitation therapists.

### **What we do know for sure?**

Rehabilitation for cancer patients and survivors has been shown to both increase quality of life and even lengthen lives. The acceptance and tolerance of long-term pain, weakness, fatigue and disability is unacceptable when so much suffering can be resolved with physical therapy. We can change this. Sandy left the cancer rehabilitation clinic with less pain, feeling stronger, more energized, confident and looking forward to getting on with the rest of her life.

### **Do you feel like you’d benefit from physical therapy?**

Like most physicians, many physical therapists specialize in certain areas of rehabilitative medicine. You will want a physical therapist that is familiar with the issues commonly facing people after surgery and radiation to the head and neck, or one familiar with treating chemotherapy related problems. A good place to start is with your cancer doctor or nurse. Your surgeon, medical oncologist, oncology nurse or even speech pathologist will likely be familiar with physical therapists in the area. Another option is the American Physical Therapy Association’s website [APTA.org](http://APTA.org). On the website’s top menu bar you can click on “Find a PT.” In step one of the search you can either enter your zip code or city and state. Step two is the “practice area” section where you should click “Cancer.” After filling in a supplied security code click on “search.” If all else fails, call the physical therapy departments in your area and ask for someone who is best trained to help you.

*Editors Note: Dr. Leslie J. Waltke is a physical therapist with a clinical mastery in oncology & founder of the Waltke Cancer Rehabilitation Academy. She is a national expert, author, speaker & educator in cancer rehabilitation & is the Cancer Rehab Coordinator for Aurora Health Care in Milwaukee, Wisconsin.*

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## Time for Sharing...Where to Begin, When to End?

All stories have a beginning and an end so where else to begin than with the writer, right? Someone must decide where to begin and who better than the person doing the writing, especially if the writer is writing their own story.

So, where do I begin? Cancer the topic, that's why we're all here, right? Before Cancer (BC) and After Cancer (AC). But when does the real story start? Do not know when the cancer first came to visit me, of course do know when it was discovered, when the operation took place, and when the recovery began. Do not know when the recovery will end, or will it?

Let's begin my story away back when I hitched a ride to California. Quite an adventure for a Buffalo boy. Not much with me: \$225.00 cash, two Army duffle bags of clothes including 2 pair Army boots, one too



small suit made in Korea, one pair of penny loafers on my feet. Dropped off at the Los Angeles YMCA, on your own now young man! No car, no contacts of any kind. You ask why....why did I take this risk, simple answer indeed, get me an education and find some girls! Eventually I did both!

Lots of trying times in the beginning, very little money, and no one to talk to: (this period of time phone calls were prohibitively expensive, letters back home rare). But I survived many a challenge, in fact, achieved my goals by never giving up.

Along the way my journey included: a first car for \$75.00, no insurance; apartment living in Hollywood and East LA; rough camping in Baja, Mexico and throughout the Southwest; meeting and marrying a wonderful woman (yes, we are still together); getting that education (AA, BA, MA, MA); leasing cars to movie stars; working for the LA Times; process server; postal

worker; almost broke many times; amateur photography awards from the LA Times; Political Science honor fraternity.

A full and adventurous time of life. Married in Trinidad, WI; graduate school in Madison, Wisconsin; back home to Buffalo when children were to become part of our future. But wait a minute, let's go back to LA because there something happened that changed my life forever and directly relates to that BIG C that so many of us have to deal with.

While leasing cars in Beverly Hills (My old car broke down thus a very attractive job) I was playing pick up basketball at Los Angeles City College. One day I felt a serious pain in my groin area, a hernia I thought. I ask my boss if he knew a doctor and he recommended one in Century City. Turned out to be the team Doctor for the LA Lakers. Having no insurance I was concerned about the bill. He quickly gave me a physical exam and commenced to question me for 30 minutes, at the end he said "you do not have a hernia but you're a tightly wired guy, and your nerves lead to physical constrictions and that tightening in your groin is causing the pain. You need aerobic exercise" "What's that?" I responded. He explained and recommended a book, "Aerobics" by Dr. Kenneth Cooper. Revelation and a change of life ensued.

Over time I became a runner. Aerobics - a game changer that never solved a problem but works wonders with your attitude towards solving them. Three days before my operation I ran 6 miles, albeit slowly. But, back to life in Buffalo.

Our family of four grew together in Buffalo: lovely wife, two great kids, always managed to live a decent life. Some ups and downs throughout the years but ultimately with my wife's intelligence and great attitude, we flourished as a happy family. Health and nutrition have always been one of the core principles of our living. We practice what we preach. Life is good, right?

Well it was, but while enjoying life there was a little sore in my mouth. That little sucker would simply not go away. For years I felt it. Dentists said, "let's keep our eye on it", biopsies said, not to worry, benign. But it would not go away. You know where this is going. Finally a biopsy that

dug deep in my jaw for sample tissue - a big ouch. It hurt.

But that pain was nothing compared to the tsunamis surprise a few weeks later. You've got the Big C! Go to Roswell Park Cancer Institute immediately. Wow.

Two weeks later I am at Roswell for tests and exams. You know the drill. Then three doctors and a nurse walk in the room. No one is smiling and in fact they all wear rather grave expressions. "Sit down" they say. I do. "Stage four cancer" they say, "but it is treatable." Squamous Cell Carcinoma!

What's it all mean? What a shock to the system. Implications? What happens next?

Remove half my jaw, replace with part of my leg or shoulder, you choose which. Radiation and chemotherapy...oh, did I forget to mention, cancer in my neck lymph nodes also. Whew!

Isn't life strange? The Moody Blues sing a song of that title, I found myself humming the melody. Who woulda guessed because otherwise I felt great!

No choice but to go forward, no way for me or any of the doctors to fully understand all the implications. The operation first and then we will have a better idea of what to do next.

The operation: 14 hours, 6 doctors, a very worried wife and family. Feeding tube, catheter, morphine, Oxycontin and who knows what else. Motionless, speechless, clueless as to the future. Just keep on truckin'. And I did.

"Change is the essence of life", so Socrates said. A bit of an understatement for me at this point: fibula gone, right jaw gone, teeth gone. Add to the mouth: part of the fibula, Titanium, eventually a prosthesis. For a while: cannot walk, cannot talk, cannot eat, and cannot fully comprehend all that is happening.

Complications, implications, emergency trips to the hospital, twice in an ambulance. Eat through a tube for six months, cannot swallow, physical therapy and learning how to walk again.

Meanwhile 33 treatments of radiation, 3 plus chemotherapy that felt anything but therapeutic!

And who suffers the most? Not me, no, not by a long shot. How about my wife, the primary caregiver. She who had to remember

continued on page 5

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continued from page 4

so much, who had to do much, who never complained, who never gave up, who continued walking on the treadmill setting a crowning example for me. While I slept most of the time it was she who was constantly on guard for every nuanced change in my situation. No relief. There are no words to express my gratitude.

During the first 7-8 months after surgery I do not think I was aware of the changes that would take place in my life AC. Somehow I believed a return to BC was on the menu. Surprise, surprise, for what I grew to understand during months 8-12 was that I was now in a "New Normal" state. Life simply would never be quite the same; in fact, the New Normal requires quite a mental adjustment. I grew to understand mentally this was more difficult than the surgery; there were no drugs to help take away the pain. Well, I suppose there actually are some drugs but therein does not lie the answer.

What to do? Start to walk, begin to drive, back to work, and yes, back to working out. No more running but how about a recumbent bike? It is all about attitude, a positive one. Just before the operation I made a decision to be a role model for my wife, children, family and friends. Positive, upbeat, go forward, even humorous. Well humorous in my mind anyway. Not sure how many laughs I got!

It was easy in the beginning; perhaps because I did not understand the concept of a New Normal. I was living on the memories of the past. Once I realized the past was forever gone, the positive role model role became more difficult. I did not feel the same and was a bit uncertain regarding the future.

Struggle is a good word, once realized that without it there is no accomplishment. So struggle I did. Up days and down. The key was consistency, never give up, always keep trying. It works.

Aerobics works. Recumbent bike, elliptical, 3-4 times a week with increasing intensity and time. Stretching and push-ups afterwards. Beginning approximately one year after surgery it was tough, I could not do a single push-up, (yesterday 28), 10 minutes of light activity was enough, (now 55 minutes). As my conditioning improved so did my attitude and the New Normal slowly became more acceptable, much less daunting. The lessons I learned away back in LA stayed with and work for me. Aerobic activity impacts attitude.

The New Normal is so very different having constant, very intimate reminders of your condition, to wit: part of my tongue is always numb, part of it always hurts, sometimes swelling up to fill my mouth. So with every spoken word there is a reminder, with every swallow and every bite chewed, reminders. The prosthetic clamped on to my remaining teeth, always conspicuous, in and out a few times a day.

Then there is the leg, fibula gone and part of that grafted into my mouth, balance never the same. I always feel unstable, wobbly, as if I drank three strong Margaritas on a hot summer afternoon. Add on constant number one or two pain, edema, especially during warmer weather or after lots of walking.

Well, you get the picture of The New Normal. A bit of an adjustment indeed yet life is good. Once I adapted, adjusted, then it is go forward time. Work, travel, working out, Oh Boy, lots to do and see. Underlying all of this and deeply influencing my life, my wife. Greater support I could not ask for.

So ladies and gentlemen of the jury, this sums up my story to date. Latent fears of the Big C returning notwithstanding, it is onward and upward. My jury is in, for those of you whose jury is out I hope this influences their decision.

~ Chuck Miller  
dangtootin@hotmail.com

## Inspiration Corner



Often, SPOHNC hears about great reading, websites or events that we'd like to share with our readers. Recently, SPOHNC's Medford, OR Chapter Facilitator, Richard Boucher, shared this e-mail and information with his Chapter attendees. If you have access to a computer, this one is well worth the time. Take a look!

Forgot to mention that we spent some time during our meeting reviewing a great website called Gratituderevealed.com.

It's a terrific collection of videos on various subjects related to happiness such as gratitude, patience, healing, love, and others. Along with the videos are quizzes, helpful hints, the science behind happiness, and sources for more info.

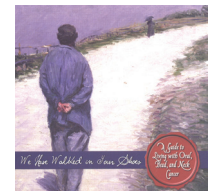
Highly recommend you bookmark and tour the site!

All best,

Richard

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- Contains the basics about the symptoms and diagnosis of head and neck cancer, types of treatment and common side effects.
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*"We Have Walked In Your Shoes" is a tremendous resource for OHNC patients."*  
~ Valerie T.

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## March is National Nutrition Month

*Excerpt from Eat Well Stay Nourished A Recipe and Resource Guide for Coping With Eating Challenges - Volume 2.*

Head and Neck Cancer patients present with a multitude of nutritional challenges. Dietitians can help the patient manage eating issues by providing an individualized nutrition plan. Nutrition interventions can aid in the maintenance of body weight, which may help prevent treatment delays and complications. In addition, providing your body with sufficient calories, protein, fluid, vitamins and minerals will support a faster recovery. If you are struggling to maintain your weight, ask your oncologist about meeting with a Registered Dietitian.

To help you along the way, SPOHNC put together 2 Volumes of our cookbook - *Eat Well, Stay Nourished – A Recipe and Resource Guide for Coping With Eating Challenges*. Both volumes are filled with delectable, tried and true recipes submitted by survivors. Designed to maintain or enhance caloric intake during and after treatment, SPOHNC invites you to dabble in some of these culinary creations.

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

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- Cancer Journeys of Survivors
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### Spinach Quiche

*9 inch pastry shell baked for 5 minutes*

- 1 ½ to 2 lbs. fresh spinach*
- 1/8 tsp. freshly ground nutmeg*
- 1 tsp. dried tarragon*
- 1 Tbsp. fresh lemon juice*
- salt and pepper*
- 2 Tbsp. chopped fresh parsley*
- ½ c. feta cheese*
- 4 eggs*
- ½ c. plain yogurt*
- ¾ heavy cream*



*Cook spinach til tender. Drain liquid thoroughly by hand squeezing. Chop very fine. Combine spinach with nutmeg, tarragon, lemon juice, salt and pepper to taste and parsley. Spread on the bottom of pastry shell. Sprinkle cheese on top. Beat eggs lightly with yogurt. Add cream and blend well. Pour over spinach mixture. Bake in 350 degree oven for 30 minutes or until custard is set. Serves 7.*

*~ Jane Mauate, TX*

### Cabbage Soup

- 1 onion, chopped*
- 2 stalks celery, chopped*
- 1 small head green cabbage, chopped*
- 1 small can tomato sauce*
- 2 (28 oz.) boxes chicken broth*
- 1 tsp. garlic powder*
- ¼ tsp. thyme*
- ¼ tsp. rosemary*
- 2 tsp. salt*
- ¼ tsp black peper*
- ½ tsp. white vinegar*
- 4 Tbsp. olive oil*



*In soup pot, put half of olive oil, celery, cabbage and salt. Simmer for 7 minutes. Add tomato sauce, chicken broth and all dry spices. Add additional salt and pepper, rest of olive oil and vinegar. Cook on low for about 45 minutes or until cabbage is very soft. Serves 10 to 12.*

*~ Micki Naimoli, PA*

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## Head and Neck Cancer News

### Cancer-causing gene found in plasma may help predict outcomes for head and neck patients

February 18, 2016 - Researchers at the University of Cincinnati (UC) have discovered that a human cancer-causing gene, called DEK, can be detected in the plasma of head and neck cancer patients. DEK may help doctors understand how a person's immune system could be used to treat cancer or predict outcomes for patients.

These results were presented via poster at the Multidisciplinary Head and Neck Cancer Symposium in Scottsdale, Arizona, Feb. 18-20.

"Head and neck cancer remains the sixth most common cancer worldwide," says Trisha Wise-Draper, MD, PhD, assistant professor in the Division of Hematology Oncology at the UC College of Medicine, a member of both the Cincinnati Cancer Center and UC Cancer Institute and principal investigator on this study. "Although, infection with the human papilloma virus, or HPV, has emerged as a factor for determining outcomes for head and neck squamous cell carcinoma (head and neck cancer), leading to less intense treatment strategies for patients, no plasma biomarkers exist to predict tumor response to treatment or possible relapse.

"One potential plasma biomarker is programmed by the human DEK gene, which has been found to promote cancer. DEK RNA and protein are highly increased in tissue specimens from several tumor types

including head and neck cancer, breast cancer and melanoma, and antibodies to DEK are also detected in patients with autoimmune diseases like juvenile rheumatoid arthritis and lupus. Our previous work has shown that DEK is highly and universally present in head and neck cancer tissue specimens regardless of stage or HPV infection and has suggested tumor-association. In addition, white blood cells (macrophages), secrete DEK protein leading to the hypothesis that DEK may be present in the plasma of cancer patients and could be correlated with aggressiveness of disease and patient outcomes."

In this study, researchers collected whole blood from either patients with newly diagnosed and untreated head and neck cancer or normal healthy participants who were the same age. Plasma was separated from the samples, and an enzyme-linked immunosorbent assay (ELISA), a test that uses antibodies and color change to identify a substance, was administered.

Plasma DEK levels were compared to normal control levels, tumor stage, age and smoking status; these levels were also compared to inflammatory markers, which can signify cancer, in the plasma and tissue.

"We found that DEK was present in the plasma of both healthy control subjects and those with head and neck cancer," Wise-Draper says. "Overall, DEK was decreased

in head and neck cancer patients compared to healthy patients, but it was inversely correlated with IL-6, which is secreted by T cells (white blood cells that play a role in immunity) and triggers an immune response, in the plasma. The immune system's reaction to the tumor also appeared to be linked with high DEK plasma levels. So, although DEK presence is increased in head and neck cancer tissue, plasma DEK levels are decreased in patients when compared with healthy individuals and are further decreased in patients with advanced cancers."

She says these findings, along with DEK's link with IL-6 levels, suggest that high DEK levels may mean better outcomes for patients.

"Furthermore, high DEK levels in the plasma may predict better immunotherapy in terms of cancer treatment," she says. "Further analyses are ongoing to determine whether DEK levels predict response to various treatments, correlate with the body's immune response and whether DEK presence in the serum (in blood, serum includes all proteins not used in blood clotting and all the electrolytes, antibodies, antigens, hormones or any external substances, like drugs) will predict remaining disease or early relapse.

"This information will be important to verify DEK plasma measurements as a clinically useful test and may give insight to future personalized and targeted treatment strategies for head and neck cancer."

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## Good News!

Life brings with it many blessings, and sometimes, we are blessed in ways we could never imagine. SPOHNC was recently reminded of this, in a very unique way. It's a first for the organization, and it was quite a lovely surprise. Below is a letter that we received, along with a gift to SPOHNC. While it was surely bittersweet for the congregation, what a special way to help us to continue our good work. It is with gratitude to Cross and Crown Lutheran Church, that we share this note with you. Thank you to the congregation for choosing SPOHNC as one of your beneficiaries.



January 2016

To Support for People with Oral, Head and Neck Cancer,

Cross & Crown Lutheran Church in Chamblee, Georgia served God's community for more than 50 years. Across that time, it built a legacy of community outreach and tithing to God's partners in the Southeastern Synod of the ELCA and around the globe.

After prayerful deliberation, the congregation decided it could best serve God through Holy Closure, sale of the church and property in Chamblee and a distribution of the proceeds to organizations that can continue God's work into the future.

Please accept the enclosed gift and use it to follow the words of Jesus ... "As each has received a gift, use it to serve one another, as good stewards of God's varied grace" (1 Peter 4:10).

If you have any questions, please do not hesitate to contact Cross & Crown Lutheran Church, 5456 Peachtree Blvd, #424. Atlanta, GA 30341.

In Jesus' name,

The congregation of Cross & Crown Lutheran Church

## Head and Neck Cancer News

### Chemoradiation may increase survival for a subset of elderly head and neck cancer patients

February 18, 2016 - University of Colorado Anschutz Medical Campus - The addition of chemotherapy (CT) to radiation therapy (RT) improves survival rates among a subset of elderly head and neck cancer patients, specifically those ages 71 to 79 with low comorbidity scores and advanced disease stage, according to University of Colorado Cancer Center research presented at the 2016 Multidisciplinary Head and Neck Cancer Symposium. While previous research has demonstrated the efficacy of combining CT with RT to improve survival for HNSCC patients, this improvement had not been shown in patients older than 70 years.

"Elderly patients have been underrepresented in prospective clinical trials that have defined standards of care for head and neck cancer,"

said Sana Karam, MD, PhD, CU Cancer Center investigator, assistant professor of radiation oncology at the University of Colorado School of Medicine, and senior author on the study. "Our study drew on nationwide data to assess more comprehensively how combined therapy impacts this population."

The authors queried the National Cancer Data Base (NCDB) for records of patients older than 70 years who were treated for non-metastatic oropharyngeal, laryngeal and hypopharyngeal cancers between 1998 and 2011. The NCDB is a jointly-sponsored project of the American College of Surgeons and the American Cancer Society that aggregates data from

more than 1,500 facilities accredited by the Commission on Cancer. Sixty-eight percent of the patients received RT alone, and 32 percent received CRT. Compared with RT alone, CRT was associated with improved survival in patients age 79 and younger with advanced disease but without comorbid conditions. Collaborators included Dr. Arya Amini, first author on the study, and Drs. Bernard Jones, Antonio Jimeno, Jessica McDermott, David Raben, Debashis Ghosh and Daniel Bowles as co-authors on the study.

Patients who did not see an OS benefit from CRT tended to be age 80 or older, had a comorbidity score of two or greater, presented with less advanced disease, or

continued on page 9

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## SPOHNC Wants to Hear From You

Have a topic you'd like us to feature? Let us know.

Have you shared your story with SPOHNC? Time For Sharing is always in need of survivor stories to share with our readers.

Chapter News or Survivor News? Special occasion or celebration? We're always looking for good news to share!

Read a great book or found a website that inspired you and helped you on your journey? We'd love to let our readers know.

Have an interesting hobby to share? Send us your photos and tell us about it.

Out of treatment for a year or more? Become a volunteer for our National Survivor Volunteer Network. Caregiver volunteers are needed too!

No SPOHNC Chapter nearby? Find out how we can help you start one.

Doing something to raise awareness? Remember to let us know and send us pictures. We want to promote you!

Need SPOHNC brochures to share? We'll be glad to send you some.

And finally...just keep in touch. SPOHNC is here to help, listen and learn from you. Call us at 1-800-377-0928, or e-mail us at [info@spohnc.org](mailto:info@spohnc.org).



S•P•O•H•N•C

continued from page 8

were treated with three-dimensional RT. Patients age 80 or older with multiple comorbidities trended toward worse OS with CRT, though the difference was only marginally significant.

Findings may aid clinicians in discussing treatment options with their elderly HNSCC patients. Moreover, results of this study could guide future prospective trials to confirm the benefit of multimodality treatment in elderly patients, not only for head and neck cancer but for other cancer sites, as well.

"Because the toxicity of concurrent chemoradiation is greater than radiation alone for definitive HNSCC treatment, many clinicians have reservations about offering CRT for elderly head and neck cancer patients," said Karam. "However, in the era of improved radiation techniques, improved systemic therapy and better

supportive care, we find that CRT does, in fact, improve survival for a large segment of this population."

The abstract, "Does Age Matter? Survival Outcomes with the Addition of Concurrent Chemotherapy for Elderly Head and Neck Cancer Patients Undergoing Definitive Radiation Using the National Cancer Data Base," will be presented in detail as a poster presentation at the 2016 Multidisciplinary Head and Neck Cancer Symposium in Scottsdale, Arizona.

*"SPOHNC  
is such a worthwhile organization  
for information, perspective and  
hope along the journey."  
~ Jeff H.*

### In Memorium



It is with great sadness that S P O H N C shares the news of the passing of Katherine (Kathy) Rosbrook, Facilitator of the SPOHNC Albany, NY Chapter. Kathy was a ray of sunshine and inspiration, supporting her group and offering her guidance as Chapter Facilitator since April of 2011. She began her journey as Facilitator to honor her brother, Bob, who is an oral, head and neck cancer survivor.

As an LPN, Kathy began her career at Westchester County Medical Center, St. Vincent's Hospital in New York and Albany Medical Center. She was also involved in real estate sales, and was a teachers aide and librarian's aide for her high school alma mater for 7 years. She did work with the State Insurance Fund in Albany, and was a LPN for a private medical practice in her community. Kathy loved to travel, and spend time with her grandchildren.

Kathy's spirit of volunteerism extended way beyond SPOHNC. She was truly dedicated to helping others, and her passion for volunteerism was apparent, through her extensive community involvement which

included the Kinderhook Kindercrafters, the Columbia County Docents, the ICE PTA and also as a founding member of Ichabod Crane's music booster club, TEMPO.

SPOHNC's Board of Directors, staff, members and the Chapter attendees of the Albany, New York group will miss Kathy dearly. Her bright smile, the spark that she carried with her throughout her day, even as she fought her own battles, and her commitment to all that she did, were a true testament to the special compassion she had for others. SPOHNC will keep her family and friends in our prayers.



<http://www.spohnc.org>

E-mail-- [info@spohnc.org](mailto:info@spohnc.org)

## Head and Neck Cancer News

### Pazopanib/Cetuximab Combo Shows Promising Efficacy in Advanced HNSCC

February 23, 2016 - The combination of pazopanib (Votrient) and cetuximab (Erbix) showed a disease control rate of 77% in patients with recurrent or metastatic head and neck squamous cell carcinoma (HNSCC), including patients with cetuximab- or platinum-resistant disease, according to a phase I study presented at the 2016 Multidisciplinary Head and Neck Cancer Symposium.

In the trial, which was the first to evaluate pazopanib in HNSCC, the response rate was 32% and the stable disease rate was 45%. Target lesion size decreased in 59% of patients, and 32% experienced a tumor lesion decrease of 40% or more.

“Time to progression was also significantly longer than what one would have expected in these patients if they had been given the traditional chemotherapy approach,” said presenter and first author Douglas Adkins, MD, Washington University School of Medicine, St Louis, Missouri.

Prior studies have shown that angiogenesis could be an important pathway of resistance to EGFR inhibitors, which established the rationale to investigate pazopanib, which targets angiogenesis through multiple targets that include VEGFR. The study used a suspension formulation of pazopanib, since patients may have problems swallowing or gastrostomy tube dependency.

The suspension formulation was not found to have altered pharmacokinetics relative to the tablet form.

The ongoing phase I study enrolled 22 patients, whose mean age was 58 years (range, 43-72). The majority of patients were male (77%). ECOG performance status was 0 for 13 of the patients and 1 for 9. Sixteen patients had a history of smoking and 6 did not.

The primary tumor sites were oropharynx (n = 6; 5 positive for p16), oral cavity (n = 8), hypopharynx (n = 4), larynx (n = 3), and nasopharynx (n = 1). The sites of recurrence were local/regional for 2 patients, distant in 11, and both for 9. Due to progression on prior therapy, 12 patients were cetuximab-resistant, 14 were platinum-resistant, and 10 were resistant to both.

The primary endpoint of the study was to establish a maximum tolerable dose (MTD) of pazopanib suspension in combination with fixed dose cetuximab (400 mg/m<sup>2</sup> cycle 1 induction followed by weekly doses at 250 mg/m<sup>2</sup>). Secondary endpoints assessed response by RECIST 1.1 criteria after each 8-week cycle and safety.

Among patients with cetuximab-resistant HNSCC, the partial response rate was 25%, and the median time-to-progression was 152 days (range, 48-282). Among patients with platinum-resistant

HNSCC, the complete response rate was 7% and the partial response rate was 21%. The median time-to-progression was 140 days (range, 13-282).

In addition to RECIST responses, cavitation was observed within the tumors on scans after the first 8 weeks of treatment. “Cavitation in the lesion is a response that I’ve rarely seen with chemotherapy with this disease, but it seems to be a class effect of VEGF inhibitors,” noted Adkins.

The largest dose of pazopanib administered in the study was 800 mg/day, which was established as the MTD; however, dose-limiting toxicities were not seen at this dose. At 400 mg/day of pazopanib, 1 of 6 patients experienced grade 3 neutropenia with infection. At 600 mg/day of pazopanib, 1 of 7 patients experienced grade 3 proteinuria. At 800 mg/day of pazopanib, 1 of 6 patients experienced fatigue.

The adverse events associated with the two therapies were not overlapping. Most adverse events attributed to pazopanib were grade 1 or 2. Fatigue and hypertension were the most common adverse events. One fistula occurred.

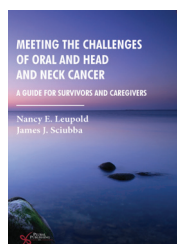
An ongoing expansion cohort that aims to enroll 9 patients is following this study. They will receive a fixed dose of pazopanib suspension, based on its MTD, and a standard weekly dose of cetuximab.

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*"My diagnosis was 5 years ago, and my SPOHNC Chapter meetings and newsletters have been a great help and resource."*

*~ Claire N.*





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