

NEWS FROM S·P·O·H·N·C



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

Baroreceptor Reflex Failure in Head and Neck Cancer Patients

Neerav Goyal, MD, MPH

Baroreceptor Reflex

The baroreceptor reflex is responsible for short-term control of your blood pressure. As blood pressure increases, arteries may become stretched. Special nerve fibers monitor for stretching along two arteries; the carotid artery and the aorta. The aorta is a big blood vessel that carries blood from your heart to the rest



of your body. The carotid artery is a blood vessel that carries blood into your neck, face, and brain. If these arteries are stretched, a signal is sent along a nerve, called the glossopharyngeal nerve, to a part of your brainstem called the medulla. The medulla has many functions, including controlling your heart rate and blood pressure. When your medulla senses that your carotid artery or aortic arch are being stretched it sends signals to make your heart rate

slow down and make your blood vessels dilate. This causes a sudden drop in your blood pressure.

Baroreceptor Reflex Failure

Baroreceptor reflex failure occurs when the baroreceptor reflex is unable to properly control your blood pressure. This can cause your blood pressure to drop unexpectedly when going from sitting to standing position. It can also make you feel lightheaded, dizzy, or cause you to faint. Some people with baroreceptor failure experience an increased blood pressure or an increased heart rate. They may develop headaches, sweating, nausea, and flushing of their skin.

Causes of Baroreceptor Reflex Failure

Surgeries that take place near the carotid body or aortic arch can cause baroreceptor reflex failure by injuring the signal pathway that controls the baroreceptor reflex. This includes surgeries and procedures such as:

1. Carotid endarterectomy (removal of plaque from inside your carotid artery)
2. Carotid body tumor excision (removal of a tumour sitting outside your carotid artery)
3. Neck dissection (removal of lymph nodes in your neck – this may be done when treating cancers in the head and neck area)
4. Radiation therapy to the head and neck area (this also may be done when treating cancers in the head and neck area)

Who is at Risk?

Anybody having surgeries or procedures that are listed above. Baroreceptor reflex failure after radiation therapy is more common in patients who are treated for Hodgkin's lymphoma or nasopharyngeal carcinoma (a cancer in the area behind the nose).

When Should You See a Healthcare Provider About Baroreceptor Reflex Failure?

See your healthcare provider if, after having surgery or radiation therapy in the head and neck area, you experience light-headedness, dizziness, fainting spells, increased heart rate, headaches, sweating, nausea, or flushing of the skin. It is important to know, that these symptoms may occur months to years after the surgery or radiation therapy.

How Is Baroreceptor Reflex Failure Diagnosed?

You may have baroreceptor reflex failure if, after surgery or radiation therapy in the head and neck area, you develop difficulty controlling your blood pressure. Traditionally, tests for baroreceptor reflex failure involved injecting a patient with different medications and monitoring for changes in blood pressure and heart rate. This is less commonly performed today.

To help determine if you have baroreceptor reflex failure, your doctor may arrange for you to carry a machine that checks your blood pressure multiple times a day while you perform your normal daily activities. Your physician may have you perform a special maneuver which stresses your baroreceptor reflex. In some people, this maneuver can cause them to become light headed or even faint, and as such it should only be performed in the presence of a healthcare professional. Another method of stress testing the baroreceptor reflex that a clinician may perform, involves placing your hands in ice water and monitoring for changes in your heart rate and blood pressure.

BARORECEPTOR FAILURE continued on page 2

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Baroreceptor reflex failure can be difficult to diagnose as it mimics other medical conditions that cause difficulty with regulating blood pressure. The most common reason for changes in blood pressure is a condition called essential hypertension. Someone with essential hypertension has high blood pressure without an identifiable reason. Another potential cause for changes in blood pressure and heart rate is a tumour of the adrenal gland which secretes hormones. To rule out the existence of an adrenal gland tumour your doctor may arrange for an ultrasound of your kidneys.

Treating Baroreceptor Reflex Failure

Baroreceptor reflex failure cannot be fixed, but the symptoms you experience can be helped. Baroreceptor reflex failure is usually treated by a cardiologist – a doctor that specializes in medical conditions of the heart and the circulatory system. Some cardiologists have a special interest in treating conditions such as baroreceptor reflex failure. Your cardiologist may work with a neurologist or other specialists to treat various conditions that cause unstable blood pressure. This group may be part of an autonomic dysfunction program.

If you are experiencing symptoms because your blood pressure is high, your doctor may start you on one or more medications such as clonidine to help decrease your blood pressure. If your blood pressure is very high your doctor may prescribe medications such as nitroprusside, phentolamine, or labetalol to help decrease your blood pressure. These medications help lower your blood pressure by relaxing muscles around some of your blood vessels.

If your symptoms are because your blood pressure is too low, you may be given a steroid to help increase your blood pressure. A medication such as midodrine may be used to help tighten muscles around some of your blood vessels which can help raise your blood pressure. Your doctor may recommend you wear compression stockings, a special sock that gently squeezes your leg and helps improve blood circulation.

Depending on the symptoms you are experiencing, your doctor may decide permissive hypertension is right for you. With permissive hypertension, a decision is made to keep your blood pressure higher than what is considered normal. Since your blood pressure is kept higher than average, a sudden drop in your blood pressure is less likely to cause significant symptoms.

Important Things to Tell Your Doctor

If you have been diagnosed with baroreceptor reflex dysfunction it is important to let your doctors know. This is particularly true if you are planning to have surgery. If you have baroreceptor reflex failure you are at a higher risk of having significant changes in your blood pressure during and immediately after, your surgery. If this is not treated, your risk of having a heart attack or stroke are increased. During, and immediately after your surgery, an anesthesiologist closely monitors your heart rate, blood pressure, and other vital signs. Your anesthesiologist will give you different medications depending on how your blood pressure and heart rate change. If your anesthesiologist knows you have baroreceptor reflex dysfunction this may help them better understand why sudden changes in your blood pressure and heart rate are happening. With this information your anesthesiologist can decide which medications are best to

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BARORECEPTOR FAILURE continued from page 2

use in controlling your blood pressure and heart rate. This is one of many ways your anesthesiologist helps keep you safe during, and after, your surgery.

How Can Baroreceptor Reflex Failure Be Prevented?

Since your brain receives separate baroreceptor reflex signals from the right and left side of your body, some people think baroreceptor reflex failure is less likely if surgery or radiation therapy are only performed on one side of the neck, or by limiting the amount of surgery performed on a side of the neck. However, this may not be possible, such as when treating certain cancers in the head and neck area.

Surgery for head and neck cancer once involved having a radical neck dissection. A radical neck dissection meant all of the following were removed from the neck during surgery:

1. All lymph nodes in the neck
2. Spinal accessory nerve (a nerve used to control some muscles that help lift your shoulder)
3. Internal jugular vein (a large vein that drains blood from your head and neck area and returns it to your heart. This vein is very close to your carotid artery.)

A patient having a radical neck dissection was at a higher risk of having baroreceptor reflex failure. Today, most patients having surgery for head and neck cancer do not need a radical neck dissection. Instead, they can have a selective neck dissection. A selective neck dissection involves only taking out the lymph nodes in the neck that are at highest risk of having cancer in them. With a selective neck dissection, the spinal accessory nerve and the internal jugular vein are not removed.

Traditionally, when treating head and neck cancers with radiation therapy, a technique called conventional radiation therapy was used. This involved using a single beam to deliver radiation from several different sides of the patient. Unfortunately, when treating a patient with radiation, parts of the body that do not have cancer, but are near the cancer, will also be affected by the radiation. This can lead to unwanted side effects. If this happens near the carotid artery, baroreceptor reflex failure can happen. As technology has advanced,

more techniques for delivering radiation therapy have been developed. Some of these newer techniques may be able to reduce the radiation delivered to parts of the body that do not have cancer. One of these techniques is known as intensity-modulated radiation therapy or IMRT for short. With IMRT, your radiation oncologist is able to use multiple beams of radiation which are shaped to allow high doses of radiation to be delivered to your cancer, while minimizing the amount of radiation delivered to parts of your body that do not have cancer. If IMRT is appropriate for your head and neck cancer, your radiation oncologist may be able to use these techniques to reduce the amount of radiation your carotid artery experiences, and decrease your chances of developing baroreceptor reflex failure.

Summary

The baroreceptor reflex is one of your body's ways of controlling blood pressure. Your baroreceptor reflex senses changes in your carotid artery or the aortic arch and works with your brain to make quick changes to your blood pressure. Baroreceptor reflex failure can be an unfortunate side effect when treating head and neck cancers with surgery or radiation therapy. This can leave you with unwanted side effects such as difficulty to control blood pressure, light headedness, fainting, sweating, and skin flushing. Baroreceptor reflex failure can be difficult to diagnose. Once baroreceptor reflex failure occurs it cannot be fixed, but your doctor may be able to help you manage your symptoms. To help with this, your doctor may have you see a cardiologist or visit an autonomic dysfunction program. If you are having surgery, it is important to

let your anesthesiologist know you have baroreceptor reflex failure. With advances in surgical techniques and radiation technology used in treating head and neck cancers, your surgeon or radiation oncologist may be able to reduce your risk of developing baroreceptor reflex failure while treating your head and neck cancer.

Where Can I Get More Information?

For more detailed information on baroreceptor reflex failure and how it impacts patients who have been treated for head and neck cancer see the article: Baroreceptor reflex failure: Review of the literature and the potential impact on patients with head and neck cancer which was published in 2017 in the Journal of the Sciences and Specialties of the Head and Neck.

Editors Note: Neerav Goyal, MD MPH completed his medical school training at Jefferson Medical College followed by a residency in Otolaryngology – Head and Neck Surgery at the Penn State Hershey Medical Center. He also completed a fellowship in Head and Neck Surgical Oncology and Microvascular Reconstructive Surgery at Massachusetts Eye and Ear Infirmary and Harvard Medical School.

His clinical focus and expertise is in the surgical management of patients with head and neck (oral cavity, oropharynx, larynx, paranasal sinuses, neck) cancers, thyroid cancers, salivary gland tumors, and skull base tumors. He also has a strong focus in the reconstructive management of patients with these diseases through the use of local, regional, or free tissue to help restore form and function.

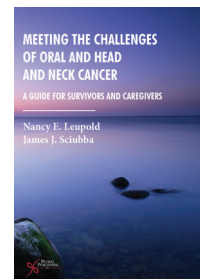
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Time for Sharing... from "Dragon Turns to Water"

I have nasopharyngeal cancer, a cancer that is located in the area in the back of the nose. It's caused by a virus, so even if you do all the right things your whole life – eat right, work out frequently, cultivate good habits – you can still contract it. The Epstein-Barr virus (EBV) is best known for causing mononucleosis, the "kissing disease." It stays in your body, but most people don't have any symptoms past the first few weeks after infection. But in my case, it made me life-threateningly ill.

I was at a point in my life where I had a lot to lose: I'd been married for 19 years and I had two young teenage boys. I was a professional chef-turned-entrepreneur. In my professional life, I acted as a teacher and mentor, insisting on clean habits in preparation and consistency in technique and method. I lived for the artistry that a kitchen can unleash— and am still trying to get back to it.

By sharing my story, I want to create a movement of knowledge and prevention. I want to create awareness about cancers that are caused by viruses that are not often screened for. But first I want to tell my personal tale and share the philosophies that have strengthened me and can strengthen others. The combination of these philosophies is what I like to call the freestyle lifestyle. The freestyle lifestyle, which helped me stay in peak condition before I got this disease, has made me strong enough to endure my battle against it. Anyone can use freestyle to feel their best during life's peaceful times— before any major emotional or physical challenges. What's more important is that freestyle can be used while people are engaged in the guaranteed battles that come with being alive.

Undergoing chemo treatments at Boston Mass General Hospital, I endured seven weeks of hell. My body, mind, and heart started to change for the worse due to the poison they put in me to destroy the

cancerous tumor. Recovery is a long road ahead with no guarantee of how my life will evolve — no guarantee of whether I could rebuild my career or sustain my family.

My journey is about the light that gives you hope during the darkness of the unknown. This unknown factor — it's the beauty and the beast in life. Like the human spirit, and like the freestyle lifestyle, it is two different sides of the same coin. This is why the freestyle lifestyle is the philosophy that guides me on my journey.

A metal machine shoots destructive rays through my skull into my soft tissue. It is damaging both my healthy tissue and the tumor the size of my thumb that sits behind my nose, just centimeters from my brain. I'm fortunate that the cancer that I'm fighting hasn't spread or my prognosis would be more terrifying. In these Proton radiation therapy sessions, I have to wear a mesh mask over my head that looks like a horror movie prop. I have a mouth piece because without it my tongue would disintegrate.

For seven weeks, Monday through Friday, I drove to Massachusetts General Hospital for these radiation treatments. I also had seven chemotherapy sessions. Before my first Proton therapy, I was anxious. The staff offered me a pill to chill me out, but I didn't take it. I knew that I had to become like water and melt into the experience on my own.

The great martial artist and actor Bruce Lee said, "You must be shapeless, formless, like

water. When you pour water in a cup, it becomes the cup. When you pour water in a bottle, it becomes the bottle. When you pour water in a teapot, it becomes the teapot. Water can drip and it can crash. Become like water my friend." For each treatment, I followed in his wise footsteps.

I was born in the Chinese year of the

dragon. Dragons are fierce and hard; they are the kings. But you cannot be a dragon all of the time. Sometimes you have to be soft and flow like fluid. To know when to be which — hard like a dragon or soft and fluid like water— is the key to my own personal philosophy, which I call the freestyle lifestyle.

When I was a kid in the '70s and my Chinese-born parents moved from Santiago, Chile, to Boston, Massachusetts with my sister and me, Lee became one of my heroes. We shared the same heritage, and I learned from his wisdom that in life's battles, we need to find the balance between the two sides of nature represented in the Taoist yin-yang symbol. A circle that is half black and half white with one dot of the opposite color decorating each side — it shows that in all things dark there is light and vice versa. Lee favored the martial arts style Wing Chun, which is soft and fluid. He was taught it by a master when he was in his teens and then created his own fighting style from it. Likewise, as a chef, I learned discipline through my teachers, many from the strict, French, old-world style of teaching in the kitchen at the Boston Ritz-Carlton Hotel. And from there, I created my own cooking style. These tools of discipline and creativity, along with others I've gathered along my path, have helped prepare me for this cancer journey. But I didn't truly know the depth of their power until I found myself on this battlefield fighting for my life.

When I was diagnosed, I explained my minor symptoms to Doctor Allen C. Lam at Massachusetts Eye and Ear.

He looked at my ear infection and prescribed me medicine. I felt like something was off, though I didn't know what it was exactly. My ear infection had cleared up, but my nose was still completely stuffed. "Doc, I'm not feeling it," I told him. I wasn't in pain, and my symptoms seemed innocuous, but in my gut I had this inclination that something was really wrong. He worked with me and looked further into my concerns. "There's a possibility you have nose cancer," he explained. Because I am a man of Chinese descent, I am at higher risk of developing nose cancer. "We need to do a biopsy, get some tissue out of there," he told me. And we were both right about my

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health. What I learned from the diagnosis process is that time is of the essence when it comes to your health — you cannot wait.

The most important part is sensing the way your body feels, to be in tip-top shape in every way — mentally, physically, and spiritually — so that you can sense shifts in your health. When you're not in tune, things happen so fast, it's oftentimes too late for treatment. Because of my sensitivity as a chef, as a religious person who appreciates art, music, dancing, sports— things that engage the body — I knew I had to trust my gut feeling and return to the doctor whose next step may have saved my life. Having that gut feeling, acknowledging it, is a simple skill. Without the softness I learned from Wing Chun, I wouldn't have been so sensitive to my body's changes, and without the dragon, I wouldn't have the raw power to fight for my life.

Losing the ability to eat was a huge blow to my confidence, but freestyle reminded me how to draw energy from other areas of my life and find other ways to maintain my strength. This includes the arts and my faith. That is how I maintain my joy today, even though it may take five years to beat this cancer and become a cancer survivor. Even though I get the best medicine, if my spiritual mind tells me that

medicine isn't going to work, I have that fear that it will return, then I am vulnerable to so much suffering. Investing in yourself is key and freestyle is all about giving yourself everything you need in life.

Cancer patients, we're all in the same family now. And when you are going through this, you need a lot of support.

One way to do that is to share our stories. This is a way to heal and gain strength. This is a new community that has nurtured me. I have a chef friend named Sean. I reached out to him when I got diagnosed. He's recovering from throat cancer. During his treatment, he lost 65 pounds. He had a feeding tube in his throat for three months. I wish he had reached out to me before! I could have been his sounding board. To just listen to him and hear his pain. I could have used his story and his thought process to get through the pain. It's not about being a best friend, it's not about someone caring about you, it's about someone wanting to be part of your journey and being there if you need them.

Even though I am so fortunate to have access to the best doctors in the world, I am the one that has to find additional ways to get my taste back, to get my body back, stronger and faster. My approach is rebuild and retrain; I cry and swear every day, but

then I regroup again. The doctors didn't tell me that I needed to go to the beach to feel the sand on my feet, but I knew that I had to do it for myself. During this journey, I realized the importance of listening to your inner gut instinct to identify what it takes to make you feel alive. I have to access all of my senses to regain my sense of taste. Most importantly, I rely on my philosophy of a freestyle life-style.

Fast forward to October 3, 2017 – My follow up with Dr. Chan: The cancer tumor has been completely 100% destroyed. The hard part is the rebuilding stage on my body, mind and soul. You are happy that the tumor is destroyed, however the battle with cancer is never over with you. You are David vs. Goliath every day in life!

I'm going to take everything about cancer and turn it upside down. I look at this experience as a blessing because I will take what I have learned here and use it every day for the rest of my life. Cancer is a gift, because it has allowed me to up my game and share my story and my methods with you. I've entered this world unexpectedly, I am accessing parts of myself I didn't before. I stand with joy in the face of this cancer.

~ German Lam

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In Memoriam **Don Pittman**

It is with a heavy heart that we share with you the loss of one of our Irving, Texas SPOHNC family members. Their beloved friend, Don Pittman, passed away in January, at 86 years young.

Jack Mitchell, survivor and SPOHNC Irving, Texas Chapter Facilitator shared the news with SPOHNC, and had these heartfelt words to say...

"For 13 years, Don was a 'regular' at the Irving SPOHNC meetings along with his wife of 67 years, Anne. Don always had a story to tell and loved visiting and chatting about everything from politics, current events, and his cancer journey. During his 14+ years of survivorship, Don was not able to eat solid food and he always kept a running count of the number of cans of Boost and Ensure that he had consumed during that time. He led a very colorful life and was involved in the

travel industry along with his wife, Anne."

Don was a wonderful husband, father, grandfather, and friend. He proudly served in the U.S. Army in Germany. It was here he and Anne found their love of travel. After his military service he worked for Continental Airlines, Six Flags Corporation and later started several successful travel agencies in Texas and Oklahoma. Their love for the industry allowed them to travel extensively

throughout the world including Australia, Europe and the Far East. They organized group charters for over 20 Super Bowls. He was also an active member of the Rotary Club for more than 30 years and a dedicated member of the First Methodist Church of Arlington.



SPOHNC's Executive Director, Mary Ann Caputo, had the opportunity to meet Don several times, remembering him as a bright and colorful character. He was always very friendly and outgoing, and loved to share stories about his travel experiences and his agency. He always had a smile on his face. He was even more interested in other people's stories and ideas. Above all he cherished and loved his family.

SPOHNC will keep Don and his family in our hearts and prayers. Rest in Peace, good friend. We will miss you.



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Head and Neck Cancer News

Possible new combo therapy for head and neck cancer

Study found an approved drug could make radiation therapy more effective

Researchers at the University of Cincinnati have tested a new combination therapy in animal models to see if they could find a way to make an already effective treatment even better.

Since they're using a Food and Drug Administration-approved drug to do it, this could help humans sooner than later.

These findings are published in the journal *Cancer Letters*.

Christina Wicker, PhD, a postdoctoral fellow in the lab of Vinita Takiar, MD, PhD, led this research which she says will hopefully extend the lives of patients one day.

"Head and neck cancer, like any cancer, is truly life-altering," she says. "Head and neck cancer could impact your throat, tongue or nose, and patients often can't swallow, talk or eat; it truly takes away some of the

most social, enjoyable parts of life."

Researchers in this study combined radiation therapy with a drug (telaglenastat) that stops a key enzyme in a cell pathway that becomes altered in cancer cells, causing those cells to grow rapidly and resist treatment. Wicker says this drug has already been studied in multiple clinical trials to see if it could improve treatment of various cancers.

"Until now, no one has examined if this drug has the potential to improve radiation treatment in head and neck cancer. Most importantly, this drug compound has been well tolerated by patients and causes minimal side effects," she says.

Using animal models, researchers found that the drug alone reduced the growth of head and neck cancer cells up to 90%, and it also increased the efficacy of radiation in animals with head and neck tumors by 40%.

"With these results, and especially with

previous clinical trials showing that the drug is well tolerated by patients, there is the potential to move more rapidly into head and neck cancer clinical trials," Wicker says. "In the future, we hope this drug will be used to make radiation treatments for head and neck cancer even more effective."

Currently, the most common treatment for that cancer is radiation therapy, but the cancer eventually returns in up to half of patients, Wicker says, and often it doesn't respond as positively to treatment the second time around.

"When [traditional] drugs are less effective, cancer growth becomes difficult to control, which can lead to the cancer quickly spreading to other organs," she says. "It is very important that scientists and clinicians develop new cancer treatments to improve treatment of this type of cancer, and hopefully our findings will provide one more option to help patients."

Head and Neck Cancer News

A promising breath-test for cancer

October 5, 2020 - by Flinders University cancer researcher Dr. Roger Yazbek. Credit: Flinders University

The global quest to use a person's breath analysis for rapid, inexpensive and accurate early-stage testing for cancer and other diseases has taken a leap forward.

In a new paper in the *British Journal of Cancer*, Flinders University researchers have reported significant progress in developing a method to test exhaled breath profiles which accurately differentiate head and neck cancer from non-cancer patients.

The Australian researchers collected breath samples from 181 patients suspected of having early-stage head and neck squamous cell carcinoma (HNSCC) before any treatment began.

"We sought to determine the diagnostic accuracy of breath analysis as a non-invasive test for detecting head and neck cancer, which in time may result in a simple method to improve treatment outcomes and patient morbidity," says lead researchers Dr. Roger Yazbek and Associate Professor Eng Ooi.

Worldwide, head and neck cancer accounts for 6% of all cancers, killing more than 300,000 people per year globally.

Tobacco, alcohol and poor oral hygiene are known major risk factors for this cancer.

A surge in human papilloma virus (HPV)-associated head and neck cancers is seeing these cancers affecting a much younger population, the researchers say.

Current therapies are effective at treating early-stage disease, however late-stage presentations are common, and often associated with poor prognosis and high treatment-related morbidity.

In the Australian study, a selected ion flow-tube mass spectrometer was used to analyze breath for volatile organic compounds. Using statistical modeling, the Flinders researchers were able to develop a breath test that could differentiate cancer and control (benign disease) patients, with an average sensitivity and specificity of 85%.

Diagnosis was confirmed by analysis of tissue biopsies.

"With these strong results, we hope to trial the method in primary care settings, such as GP clinics, to further develop its use in early-stage screening for HNSCC in the community," says co-lead author Dr. Nuwan Dharmawardana.

###

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**Fabulous February Recipes 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

Hot Crab and Avocado Casserole (from Volume Two)

1/3 c. chopped onion
1/3 c. chopped red bell pepper
1 tsp dried thyme leaves
2 Tbsp. butter
2 c. milk
3 Tbsp. flour
3 (5.5 oz.) cans crabmeat, drained and flaked (or
imitation crabmeat)
2 small avocados, peeled, pitted and chopped
2 Tbsp. lemon juice
Salt and cayenne pepper to taste (optional)
Shredded cheddar cheese



Saute onion, bell pepper and thyme in butter in medium saucepan until tender, about 5 minutes. Stir in flour and cook 1 minute. Add milk gradually. Heat to boiling over medium heat, stirring constantly. Stir in crabmeat, avocados and lemon juice. Season to taste with salt and cayenne pepper, if desired. Spoon into lightly greased 1 quart casserole dish. Sprinkle with shredded cheddar cheese. Broil for 2 minutes or until golden brown.
Serves 6. 259 calories/serving.

~ Meg M., NY

Chocolate Bread Pudding (from Volume One)

2 c. milk
6 slices bread, cubed
½ c. sugar
1/3 c. cocoa
2 egg yolks, slightly beaten
1 Tbsp. butter, melted
1 tsp vanilla
2 egg whites, beaten



Scald milk. Remove from heat. Add bread and beat until smooth. Add sugar, cocoa and egg yolks. Beat until well blended. Add butter and vanilla. Fold in beaten egg whites. Pour into 8" square baking dish. Set in a pan with about an inch of hot water. Bake at 350 degrees for about 40 minutes, or until firm. Top with whipped cream and maraschino cherries. Serve warm or cold. Serves 6. 235 calories/serving.

~ Sue B., IL



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Head and Neck Cancer News

Patients with Cancer Less Likely to Enroll in Clinical Trials Due to COVID-19

November 19, 2020 - Hannah Slater

According to a survey, nearly 1 in 5 patients with cancer reported that the pandemic would make them less likely to enroll in a clinical trial.

A research letter published in JAMA Oncology suggested that as long as high rates of coronavirus disease 2019 (COVID-19) cases exist, patients with cancer will be less likely to consider trial participation even when sites return to what they were before the pandemic.¹

According to a survey conducted by the investigators, nearly 1 in 5 patients with cancer reported that the pandemic would make them less likely to enroll in a clinical trial. The top reason provided for not enrolling was fear of COVID-19 exposure.

“While most patients would still be willing to take part in a clinical trial during the pandemic, the fear of COVID-19 exposure that would come with participating in a clinical trial is poised to cause many otherwise interested patients from enrolling. This means that trials that already struggled to find enough patients are likely to see reduced enrollment as long as the pandemic continues,” co-author of the article Mark E. Fleury, PhD, policy principle for emerging issues at the American Cancer Society Cancer Action Network (ACS CAN), said in a press release.² “The barriers patients already faced pre pandemic made it challenging to take part in clinical trials. Now with the addition of COVID-19, it is even harder and we’re likely to see long-term impacts on the pace of research.”

The survey participants were included from the ACS CAN Survivor Views panel, established in September 2019. Respondents were 18 years or older, had been diagnosed with and/or treated for cancer within the last 5 years, and were US residents.

Participants were asked a series of COVID-19 related questions regarding disposition toward trials, willingness to participate, and reasons for not participating in addition to the questions already provided in the existing survey program. The survey was sent to a total of 3054 individuals on May 27, 2020, through June 17, 2020; 933 responses (30.6%) were received.

Of the 933 respondents, 675 (73.1%) were female, 33 (3.6%) self-reported as Black, and 284 (36.6%) had an annual household income of \$60,000 or less. Among the total cohort, 316 (33.9%) respondents reported a prior conversation with their physician about clinical trials, and 192 (20.6%) were offered trial participation.

Of the 192 respondents offered a trial, 150 (78.1%) indicated they said yes and 116 (60.4%) reported they eventually enrolled, resulting in an overall participation rate of 12.4%. Moreover, of the 662 respondents not offered trial participation, 519 (78.4%) reported being somewhat or very likely to enroll if offered a trial.

All survey respondents were asked if the pandemic made them more or less likely to participate in a clinical trial, or if it made no difference. Among 907 respondents, the majority (79.5%) indicated the pandemic made no difference. The remaining respondents were more than 7 times more likely to indicate that the pandemic made them less likely to enroll in a clinical trial (18.1% vs 2.4%).

“The pandemic caused many institutions to stop enrolling new patients on clinical trials, and the assumption was that once facilities reopened, they could get enrollment back to normal. What we’ve found is that so long as the pandemic is still underway, fewer patients are going to volunteer for clinical trials,” said Fleury. “The solution is that we need to get the pandemic under control or find innovative ways like telemedicine visits so that patients can take part in clinical trials without feeling exposed to additional COVID-19 risks.”

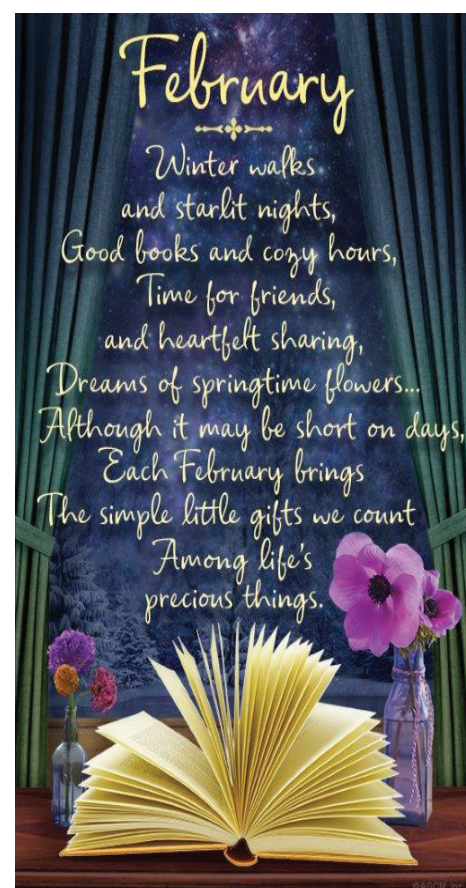
Of note, response patterns were found to be similar across demographic, socioeconomic, and care settings, as well as in the subset of 150 participants who previously agreed to trial participation. Among the 164 respondents less likely to enroll, the most common reasons provided were fear of increased COVID-19 exposure (70.1%) or difficulty accessing care during the pandemic (18.3%).

“The National Cancer Institute and the US Food and Drug Administration have provided guidance on increasing

flexibility for trial investigators during the COVID-19 pandemic,” the authors of the article concluded. “These guidelines focus on reducing COVID-19 exposure or offering alternative care settings. Trial sponsors will need to take full advantage of the approaches indicated in these guidelines to better address patient fears about clinical trial participation while the COVID-19 pandemic endures.”

References:

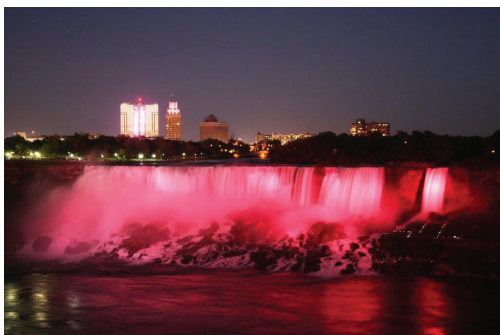
1. Fleury ME, Farner AM, Unger JM. Association of the COVID-19 Outbreak With Patient Willingness to Enroll in Cancer Clinical Trials. *JAMA Oncology*. doi: 10.1001/jamaoncol.2020.5748
2. Nearly 1 in 5 cancer patients less likely to enroll in clinical trials during pandemic [news release]. Washington, DC. Published November 12, 2020. Accessed November 13, 2020. https://www.eurekalert.org/pub_releases/2020-11/acs-nli111120.php



Coming Soon!!!! **Our Nation Shines a Light** **on April Oral, Head and Neck Cancer Awareness**

By now, we all know that April is designated as Oral, Head and Neck Cancer Awareness Month by SPOHNC. This is in honor of the month that our Founder, Nancy Leupold, was diagnosed with this devastating disease, prior to the day that SPOHNC, and Nancy's dream of supporting patients and survivors and their loved ones, became a reality. We have grown so much since then, and our programs and services have reached thousands of newly diagnosed patients across the country, and even the world. Our SPOHNC Family continues to grow and change, to meet the needs of all who come to us seeking hope, help and a listening ear.

As part of our April Awareness campaign, SPOHNC has had the privilege of being



represented by Illuminations in unique locations across the country. How wonderful it has been, to raise awareness through places like Niagara Falls in the last few years, and joining them last year, the Superdome in New Orleans, and the I-35 St. Anthony Falls Bridge in Minneapolis, Minnesota. These amazing venues were lit up in our SPOHNC colors at some point in April, helping to raise awareness, and honor those who have been affected by the diagnosis and treatment of oral, head and neck cancer.

This year at SPOHNC, we thought that now more than ever, we are all seeking hope, and so we decided to expand our illumination campaign. We are naming this effort our **2021 SPOHNC Illumination Family** and hoping to expand our reach. Our goal is to have at least one Illumination in every state where we have a SPOHNC Chapter Support Group.

We are asking buildings, bridges, towers and many special venues across the country in states and/or cities where our SPOHNC Chapter support groups are located, to join our

Illumination Family and raise awareness of Oral, Head and Neck Cancer in the month of April, by lighting their building, bridge, water tower or special venue in burgundy (or red) and white, for a day, a week, or the month.

Our family has already grown exponentially over last years, and so far we are proud to welcome more than a dozen venues, nationwide! Below are our current 2021 SPOHNC Illumination Family members and the dates they will be honoring April Oral, Head and Neck Cancer Awareness. If you live near any of these places, and feel comfortable doing so, we would LOVE to have photo representation to share in an upcoming issue of our newsletter, as well as on our website, Facebook and Instagram. Take a short ride, take a photo, and share it with SPOHNC! We will thank you for your efforts with full photo credit wherever the pictures are posted, and will send along a special surprise for you as well!

Visit these places if you can – and send your photos to info@spohnc.org.

Niagara Falls, NY and Canadian sides
April 1st – 10:00 to 10:15pm

The McDonnell Planetarium at the St. Louis Science Center, MO
April 1st

The Helmsley Building, NYC
April 2nd

The City and County of Denver Building, Denver, CO
April 3rd and 4th

The I-35 St. Anthony Falls Bridge, Minneapolis, MN
April 4th

The Baltimore, MD City Hall Dome –
April 5th – 15th

The Zakim, Longfellow and Fore River Bridges, Boston, MA –
April 8th

The Gilbert, AZ Water Tower
April 8th – 10th

The Sperry Tower, Eagan, MN
April 9th

Wells Fargo's Duke Energy Center, Charlotte, NC
April 13th

Columbia Center, Seattle WA –
April 19th

SPOHNC is excited and honored that each of these venues chose to join us all to raise awareness of Oral, Head and Neck Cancer in 2021. We expect this family to continue growing over the coming weeks, and we will keep the good news coming to you through Facebook, and eblasts. Be on the lookout for more!

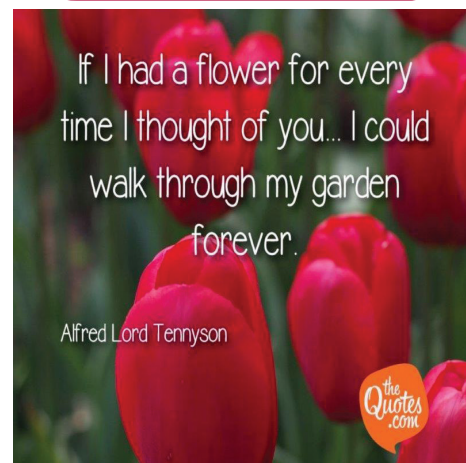
Welcome all, to our nationwide campaign, and to our 2021 SPOHNC Illumination Family.

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Head and Neck Cancer News

Channeling the immune system for head and neck cancer

November 24, 2020 - University of Cincinnati Researchers have discovered new clues into why some people with head and neck cancer respond to immunotherapy, while others don't.

University of Cincinnati researchers have discovered new clues into why some people with head and neck cancer respond to immunotherapy, while others don't.

Findings published in the Journal for ImmunoTherapy of Cancer show that it could all come down to "channeling" the power and function within one particular type of immune cell.

Laura Conforti, PhD, professor in the Department of Internal Medicine at the UC College of Medicine and corresponding author on the study, says understanding these mechanisms could help in creating combination treatments to more effectively treat some patients with cancer.

She points out that head and neck cancers are the sixth most common cancers in the world, affecting about 53,000 Americans every year. To combat the deadly disease, doctors often turn to immunotherapy, which boosts the body's own immune system in an effort to identify and kill cancer cells.

"Our immune cells are naturally programmed to distinguish between our body's 'normal' cells and what they see as 'foreign' cells and attack only the foreign cells," explains Conforti.

She says the immune cells -- called T cells -- lead the body's attack against cancers but the impact of that attack can be proven futile if a molecule in cancer cells is able to bind to an immune checkpoint in the T cells and effectively "turn them off like a light switch." As a result, the T cells leave the cancer cells alone, which Conforti says is "a major problem," especially for head and neck cancers.

A known immunotherapy treatment (pembrolizumab) targets the checkpoint molecule and blocks the "off switch" of the T cells, but scientists are trying to determine why this method works in some people and not in others.

Conforti further explains that the ability of these T cells to attack and destroy cancer cells relies on molecules called

potassium ion channels, which are present in T cells and are responsible for a variety of functions, including killing cancer cells.

Conforti's team includes co-lead authors Hannah Newton, PhD, a recent UC doctoral graduate; Vaibhavkumar Gawali, PhD, postdoctoral fellow; and Ameet Chimote, PhD, research scientist in Conforti's lab.

The team found that when patients with head and neck cancer were given immunotherapy at UC Medical Center, T cells in these patients showed increased activity in these channels, allowing them to more effectively reach the cancer cells and kill them.

The team also found that after the treatment was delivered to patients, these channels in the T cells circulating in their blood were more active, meaning they were more equipped to continue fighting off the cancerous cells.

"We also saw that head and neck cancer patients who were responding to this immunotherapy, meaning their tumors were shrinking, had greater channel activity in their T cells soon after treatment, and the T cells had more ability to enter into the tumors to continue killing cancer cells," Conforti adds. "However, patients who did not respond lacked this increased activity."

"Immunotherapy is not one-size-fits all, since some patients respond to immunotherapy, while others don't, but our research shows that ion channels within T cells of these patients play a crucial role in the response of immunotherapy. Now that we know the benefits of these channels, more research is needed to look at ways we can activate them or create combination therapies to help patients increase their chance of survival."

Team member Newton, who recently completed her doctorate at UC and is now working at the National Institutes of Health-sponsored Frederick National Laboratory for Cancer Research, says that working on this study at UC was invaluable.

"This research allowed me to collaborate with diverse professional individuals including medical oncologists, clinical coordinators and other researchers

and gave me the opportunity to better understand the bench-to-bedside procedure for drug development," Newton says. "Most importantly, it could help clinicians determine more personalized and effective treatment combinations for patients with head and neck cancer."

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game changer for the rest of this
journey!!!"*

~ Connie Lunt



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