

# NEWS FROM S·P·O·H·N·C



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

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## Returning to Work After Cancer Treatment: Ways to Ease Your Transition

Nicole Van Hoey, PharmD

### Introduction

In 2017, more than 55,000 adults in the United States experienced head and neck cancer; life after cancer treatment likely was unique for each one of them. One commonality, though, might be this: most cancer survivors are eager to establish or renew a routine that says to themselves and others, “I’m not a cancer patient any more.”



For many adults, returning to work fills the need to be “normal” again. In fact, returning to work offers many benefits: a self-confidence boost, valuable social interactions with people you consider peers, not fellow patients, and a schedule that doesn’t revolve around doctor visits. The decision to return to work isn’t simple though. Factors like finances, physical stamina, and even changing interests contribute to the decision.

Before jumping back into your pre-cancer career with both feet, consider these options and planning strategies to get the most out of the survivorship years ahead.

### Deciding to Return to Work: What’s Your Best Fit?

Going back to work is not an option for every cancer survivor. Sometimes, physical, mental, or emotional effects of cancer treatment change or delay your work plans. If you are ready, you have more options than simply a return to your old life: Some cancer survivors are excited to return to work; others prefer to

embark on a new career. Still others are called to volunteer or become an advocate.

With the mix of excitement and relief experienced after cancer treatment ends, a return to your old work place may seem like the natural next step. But take time to ask yourself what your options really are:

- Do you miss your career? And your employer?
- Is it time to find a new spot within your field? Are you looking for an even bigger change?
- Is this the right time to embark on a new career field entirely?
- Are you called to advocacy work in a cancer field or otherwise?

Regardless of your choice, all serve to offer normalcy or purpose after a period of putting your life on hold.

The decision to return to work after cancer treatment ends is not entirely made according to desire, though. Many survivors *must* return to some type of employment to cover financial and sometimes insurance needs. When you have to, or feel ready to, return to a career, remember that the change won’t necessarily be simple: You will face social, physical, emotional, and logistical challenges to re-entry, but you are not alone, and you are not the first cancer survivor to tackle this challenge.

Even if you are not excited about returning to work that is necessary because of financial needs, you may find that the routine and social support are positives that result. If and when you do feel ready to return to work, the first step is to get your doctor’s approval. The timing of your return can depend on long-term treatment side effects, physical demands or stress of the job and your need for follow-up care; talking through these options with your doctor before you approach your workplace is a good way to get yourself ready for questions to come.

### Advance Planning: Smooth Out Bumps for You and Your Employer

Whether you have a position waiting with your existing employer or you need to explore new options, some early hurdles to career re-entry as a cancer survivor are about how much information you will share about your cancer history and what adaptations you need to make your return easy for everyone.

Legally, you do not need to disclose your health history to your employer. However, disclosing your cancer information does allow you to take advantage of accommodations available to you as a cancer survivor under the Americans With Disabilities Act (ADA). Sharing your cancer history just with your direct manager and with human resources can offer you a balance of privacy and support in your professional home. Examples of ADA accommodations offered to patients with cancer include:

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- flexible scheduled hours around doctor appointments.
- part-time days or scheduled breaks for nutrition, medicine, or therapy.
- alternative desk options or even entirely different positions in the company.

Planning for these accommodations ahead of time can help you determine what work schedule or position can serve both your and your employer's needs. Before your return, reach out to the human resources department and your direct supervisor to discuss details about your daily schedule. Be creative in making an appropriate schedule to have the most successful transition.

At your first meeting, bring along a doctor's letter of approval to work, and consider bringing along an existing summary from your last doctor's visit too. This summary lists your cancer type and the treatments you received, as well as a plan for future follow-up care. This follow-up plan can help you formulate your early work schedule. Examples of onboarding options that allow time to adjust to longer work hours and maintain a treatment or therapy schedule include part-time days for the first few weeks; flex time that allows full days of work mixed with long weekends; or unpaid leave for follow-up appointments, if your company offers that option and you have not yet used it during cancer treatment. Consider flexible options that help your team, too, like sharing a position with an existing employee while you reacclimate to projects. Last, identify potential physical challenges to your work environment and develop workarounds before you arrive on the first day.

**Physical Readiness: What to Consider Before You Return**

Just because you feel ready to introduce a work routine again doesn't mean your cancer side effects disappear. You may have undergone surgery, radiation, chemotherapy or many combinations of all three; working after surviving cancer means adjusting to physical and sometimes cognitive or mental late effects of cancer treatments, or to new and sometimes long-lasting limitations.

Physically, you may need to adjust your work schedule to attend doctor visits, provide rest periods, or obtain follow-up care like physical therapy, speech therapy, or counseling. Although radiation therapy has improved and damage to healthy tissue is less common than in past decades, the physical effects still develop in many patients. Survivors of head and neck cancer specifically cope with side effects of radiation or surgery that can cause dry mouth, swallowing difficulties, or bone and tissue pain in the jaw or throat; lymphedema; reduced range of neck motion; and dental issues like tooth loss or infection. Swallowing, tongue and mouth, or dental side effects can make luncheon settings uncomfortable, especially at first. Changes to your voice, speech, or ability to talk for long periods can affect your job too if you are a frequent meeting presenter, for example. If you experience lymphedema, which can develop even a year or more after your treatment ends, pain can distract your focus at work and can physically affect your ability to lift items or move.

The emotional aspect of facing these challenges should not be underestimated either, especially if treatment has made simple pleasures like eating lunch and tasting food, or talking with colleagues about your weekend a burden. Working with your manager before you return to plan for these situations and

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possibly reassign job roles at the start can avoid uncomfortable situations for you as you return. Consistent follow-up with your manager can reassure you and your team that you are coping well physically with your return and can address any new issues that develop as early as possible.

Ahead of time, consider physical logistics with your manager:

- Can you drive to meeting locations or do you need a Wi-Fi option like GoToMeeting or a carpool?
- Can you stand for presentations or would a chair be helpful?
- If talking is too strenuous, can you deliver weekly summaries by email instead and then discuss more briefly in person?
- Can the team know that you'll need gum to help treat your dry mouth to avoid appearing rude in staff meetings?
- Can you take time off for physical therapy early with a goal of self-treatment for lymphedema later on?
- Is there a place in the shared kitchen where you can keep and secure your treatments or comfort needs, like baking soda/salt water mixes for your mouth, saliva replacements or lip moisturizers and a toothbrush for dental hygiene?
- Are you allowed to use a humidifier in the office if you need one?
- Can you step out of meetings or activities if you need to rest or rehydrate?

**Coping with Mental Aspects  
of Being a Working Cancer Survivor:  
Acceptance and Strategies**

Cognitive changes from late effects of cancer treatment, from continued pain medications, or even simply from fatigue—which is not like tiredness that rest relieves—should be anticipated, not hidden. When you return to work, expect to use more lists and notes as memory aids, to take extra breaks after intense brainstorming sessions, and to set alarms to remember not only appointments but also breaks for nutrition, hydration, and stretches.

Trying to return to work with these challenges can increase anxiety and depression, in part because they eat away

at your own confidence in your ability to perform job duties or participate on a team. Don't hesitate to discuss fears or mood changes with your doctor before they start to affect your work performance or interest in the job either. Private counseling, support groups and other opportunities to discuss these feelings can reduce their impact on your job performance and outlook.

**Interacting With Colleagues:  
Anticipating Questions  
and Staying Positive**

Sharing your cancer story can be emotional. It doesn't always offer the clean break from patient to colleague that some survivors seek in a return to "normal" work. Remember that you set the tone, and the depth, of discussion. If you want others to talk about your experience, then you can lead the discussion and keep it positive and looking ahead to the future. If you aren't generally personal at work, it's okay to stay private about this aspect of your life, too.

As a cancer survivor, you get to decide how much to share with coworkers about your work leave and treatment experience. Like your workload, your first social interactions and your cancer story should be prepared and adapted before you return. Consider these options:

- Telling everyone through email before you return.
- Telling only colleagues on shared projects.
- Asking your manager to explain your return and change of duties beforehand.

If you approach these challenging interactions with a positive manner, your colleagues also will relax and be able to enjoy your return. Co-workers may feel confused about why you left or concerned about how your return will affect their jobs and their roles. Keep your explanation for your departure and return simple and positive; try to connect with coworkers in the roles they have now, not the ones they had when you left.

Although social support is an important benefit of returning to work, coworker sympathy can be an unexpected source of frustration when you are seen as different and reminded of your status as a patient.

It's okay to tell coworkers that discussions about your cancer experience make you feel uncomfortable, or to turn down offers of a luncheon or office celebration in your honor. Your manager can help you reinforce these preferences if you need extra support.

**Discrimination or Bias:  
Facing Concerns Head-On**

Many cancer survivors fear bias in the workplace from coworkers or managers because of their cancer history. Discrimination often is a subtle undercurrent, not blatant actions like demotions. Some possible expressions of bias include comments by colleagues about your ability to contribute, promotions you consider yourself qualified for that were only offered to other employees, or even jokes about your "time off" for cancer treatment that make you feel uncomfortable. If you feel that your work situation is discriminatory in some way, take notes and develop a collection of facts that support your belief. Taking details like that to the human resources department, which has protocols and experts ready to address possible harassment or bias claims, is a solid first step toward clarifying possible harms and solutions in a professional way.

Even if you don't face direct bias or harassment, you may experience awkward situations that appear discriminatory when colleagues don't know what to say or how to act around you. This is particularly likely if your physical appearance, or even your voice, has changed enough to make your cancer history more noticeable; for example, you may return to work with a hoarse or rough voice, skin rashes or discoloration after radiation, or extreme weight loss after chemotherapy.

Facing questions about these changes is natural, but sometimes even simple questions about your absence can trigger an emotional response and be hard to address on the spot. Being prepared for these experiences ahead of time can help you worry less about derogatory remarks and help colleagues understand how to approach you in a more positive and natural way. Before you return to work, practice ways to approach these interactions so that you aren't caught off guard with questions. For example, you and your spouse, counselor, or close friend can role-play a conversation you might have with a colleague on your first

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day back. You may be comfortable using a standard phrase, like “Treatment was hard, but I’m feeling strong and healthy now as a cancer survivor.” Also consider speaking with your team manager about what you are willing to share with the team, to keep a consistent message and to increase your colleagues’ confidence in working with you and discussing your history.

**Conclusion**

Whether you’ve spent a few weeks or more than a year out of work because of cancer treatment, the return to a workplace is naturally full of anxiety about the unknown. Most if not all of the challenges you face on your return to work have happened to other survivors before you. Don’t be afraid to bring up difficulties caused by your cancer or treatment for as long as you need to become comfortable at work; don’t hesitate to find the support you need outside of the workplace

and have a soundboard for private worries or discrimination concerns. Remember that your new work routine might not be what it was before cancer, but that routine is still an important sign of your transition from a cancer patient to a survivor—and a valued colleague and employee.

*Editors Note: Dr. Nicole Van Hoey is a freelance medical writer and editor in Arlington, VA. She specializes in writing consumer/patient health material in plain language and in developing educational projects for health professionals to encourage patient education and outreach. Dr. Van Hoey has published with Remedy Health Media, ASCO Cancer.Net, America’s Pharmacist, and more consumer and academic medical publishers. Her research fields include oncology, allergy/immunology, cardiology and drug information.*

**Head and Neck Cancer News****Jim Kelly announces his oral cancer has returned**

March 1, 2018 - Hall of Fame quarterback Jim Kelly is facing another battle with cancer. The Buffalo Bills’ legend issued a statement announcing that unfortunate news.

“As our family has faced many trials and triumphs throughout the years, you have blessed us with your prayers. We are asking for those prayers once again. The oral cancer we hoped would be gone forever has returned. Although I was shocked and deeply saddened to receive this news, I know that God is with me. I continuously talk about the four F’s: Faith, Family, Friends and Fans. With all of you by my side, we will fight and win this battle together. Staying ‘Kelly Tough’ and trusting God will carry us through this difficult time.”

Kelly, 58, had a portion of his jaw removed after an initial bout with squamous cell carcinoma in 2013. The cancer returned in 2014, forcing him to go through a round of chemotherapy and radiation treatments. It was announced that he was cancer free in September 2014.

The Bills released the following statement: “We are deeply saddened to hear the news about Jim Kelly and his impending battle with cancer. Jim is a tough and courageous man and we know he will fight this battle with strength and determination.

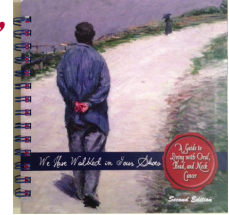
The Buffalo Bills will support the Kelly family during this trying time and we ask our fans to pray for the family as Jim begins the treatment process and the road to recovery.”

*Editors Note: SPOHNC was deeply saddened to hear the news of Jim Kelly’s recurrence. Jim is our friend and partner through the Your Cancer Game Plan campaign and our partnership with Merck. We send our continuing prayers and love to our dear friend as he remains “Kelly Tough” through this part of his journey. SPOHNC is with you all the way!*



*photo courtesy of Brian McMahon, Survivor*

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



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

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is enough to drive away  
many shadows.

— SAINT FRANCIS

## A Time For Sharing... David's Journey

I had a sore throat in 2000 for almost the entire year. I saw at least four doctors without finding a reason why my throat was sore. They ran numerous tests, but they all returned negative. My primary provider sent me to the head of ENT and initially, they thought it was an extremely rare condition: arthritis of cricoid bone, which is the cartilage of the larynx in the neck. So I lost another six months without the correct diagnosis.

In 2001, I was having neck surgery to repair a bulging spinal disc. At that time, they did a biopsy of the base of my tongue. The results came back: Squamous cell carcinoma at the base of the tongue. I received six weeks of radiation and continued on with my life because I was 99% cured.

In 2005, the cancer returned and I had an 18 hour surgery to remove 1/3 of my tongue. It was time to change my eating habits to soft foods only. Talking was more difficult and my food had to be blended. I was now 62 and chose to retire from my professional truck driving career.

In 2008 the cancer returned in the same spot. I changed medical centers and a total glossectomy was performed. The treatment this time was chemotherapy and radiation therapy. Five years later, I'm still cancer free with a 99% cure rate.

Since the metal jaw stabilizer started protruding from my jaw, I had it surgically removed in 2010. I wasn't able to maintain my weight with soft oral foods. In 2011 a feeding tube was placed in my abdomen and I was taking only canned tube feeds. I visited the ER multiple times because of stomach problems I was having with the formula. At one point my intestines flipped over on themselves, requiring another surgery to reverse this. It wasn't until I attended SPOHNC's 20th Anniversary Conference and Celebration of Life in New York that I observed a survivor putting blended table food into his feeding tube. We talked and since then I've been blending my own combination of food and haven't had a single stomach problem. What I learned from this

experience is that you need to keep trying different ways of doing things and see what works best for you.

In 2013 after having a trach for six years, I was finally able to breathe on my own without it. The appliance was removed and I was left with an open stoma. In April 2013, due to radionecrosis in my neck region, I needed a flap repair and stabilization of the spine, a complication from my 2001



surgery. I had a lot of mouth bleeding two months before the surgery. Knowing that head and neck cancers most often spread to the lung, we were always concerned about lung infections. So when I got a bump on my lower eye-lid, near the tear duct, I thought nothing of it. When I had it removed, we were informed the cancer had spread to the tear duct. This also is very rare, we were told.

In December, they removed my tear duct and once again, the treatment was radiation and chemotherapy. My fear was that the radiation would damage my vision – it didn't! This time a chemo drug that had not been available in 2008 was used.

A year later in October 2014 the cancer had spread to my cheek. The only treatment was surgery. The frozen section from surgery was negative, so we had hopes of 99% cure. Several weeks later we were informed the final pathology had come back and they were not able to remove all the cancer cells. Knowing that we had exhausted any more treatments with radiation, chemotherapy or surgery we researched clinical trials and decided to tap into gene therapy. I was a match to a medication that was used for liver cancer and in January 2015, I started to take 2 pills a day of the medication. I was so excited with this wonder drug, I had a great outlook. After being on the medication for 4 weeks, the cancer had spread to the skin on my neck manifesting as blisters. I was given 3 to 6 months to live.

### David's Thoughts

In 2001 when they first told me I had cancer, I didn't get all sad and cry and go crazy. My wife, Georgia, a pediatric nurse practitioner was upset. I knew at that moment it would

change my life and I knew I had to be strong, positive and fight this. Sometimes, though, I wonder after all the surgeries and chemo and radiation, why am I still here on this earth? Whatever God's plan is, I don't know. What I do know is I have the best caregiver in the world. I've had excellent care from all the doctors, nurses, my social worker and my supportive wife who has been with me assisting in all my care.

Head and neck cancer is not easy. I have been fighting this for 14 years. Of all the cancers, I think it's the hardest to deal with because it affects our social life, my communication, and my eating habits. We take for granted being able to talk, eat and drink. With the feeding tube I'm often asked if I am hungry. I have lost that sense – I eat to maintain my weight.

Many people have been praying for me all these years. I continue to do some of the things I used to do like "shop until I drop," clean house, and walk the dogs. I want to go back to the gym five days a week, like I'd done in the past.

My cancer has recurred four times and it makes me wonder since the doctors say after 5 years, the cancer shouldn't come back. But after the first recurrence, it's always in the back of my mind. This has not been an easy journey. There have been a lot of angry, painful, and sleepless nights. There have been times when I couldn't eat or swallow. There have been times when I've cried, especially after they removed my tongue and I couldn't talk with my grandchildren, family or friends. Communication has been the hardest part.

I remember going to my first SPOHNC meeting in New York and seeing the 15-year survivors and the 20-year survivors celebrating – how hopeful. When I was first diagnosed, we wanted to know all the survival rates and percentages and what my outcomes would be. After the cancer has reoccurred numerous times, we realize no one really knows what the outcome will be.

I would like to thank all the doctors and nurses and friends who prayed for me and who have helped care for me. Most of all, I want to thank my wife, my caregiver, who keeps me on the right path and my daughter Ashley who was so attentive with her visits with little Heath.

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### Georgia's Thoughts

Even after five surgeries and the diagnosis of cancer and it's spreading, you never get over the news. It's devastating, you realize the 99% cure may not really happen, but you always hope for it.

Head and neck cancer is the most impacting, physically because you can't hide it. It affects every part of the family's existence.

There's the fear of choking. Like the time on Father's Day when David was chewing on soft sirloin and started to choke. I'm a nurse, but I couldn't think of what to do! Then my daughter yelled, "Mom, do the Heimlich!" Needless to say, the dog enjoyed the rest of the sirloin.

Then whenever we left the house there's making sure he has all his supplies – suction machine, catheters, medications, rinse and bottles of water.

It affects communication. We both get so frustrated with me not understanding him and his trying to convey his needs. With all the high-tech devices (we trialed them all), he settled on communicating with pen and paper. He keeps in touch with the rest of the family by texting.

Since I worked full time there is my own fear of having him home alone. At one point I needed to stay by his side for a month. With the radionecrosis, his throat membranes were so fragile, he bled intermittently, but

intensely. His last surgery had an impact on his blood pressure. Since it was so low he would pass out and fall. At night, I would jump out of bed because he had fainted in the bathroom. He wasn't very happy about using a wheelchair to scoot into the bathroom at night – at least I could sleep knowing hopefully he wouldn't pass out!! That is now somewhat under control with medications every 3 - 4 hours.



After each surgery, it takes longer for his body to recover. After the first two, he bounced back quickly, but after the 3<sup>rd</sup> and 4<sup>th</sup> it took a lot longer.

Every month he would wait for the SPOHNC newsletter to see if there were any new cancer treatments for him to try. I often told him that he should be on the board since he has so many different experiences during his cancer journey. We attended the

local support groups in Cleveland.

*David was so strong. At the memorial that the staff on Seidman 5 at University Hospitals had in his honor, what struck me the most was one of his ENT providers said "David never complained, he just reported symptoms." David didn't ever want to give up. Even after they discontinued the experimental drug, he didn't want to stop taking it. Just before going into hospice, David asked the oncologist that if a cure were found would he notify him immediately! He had HOPE until the end.*

~ Georgia Davis  
nursemom520@yahoo.com

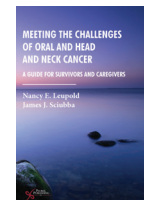


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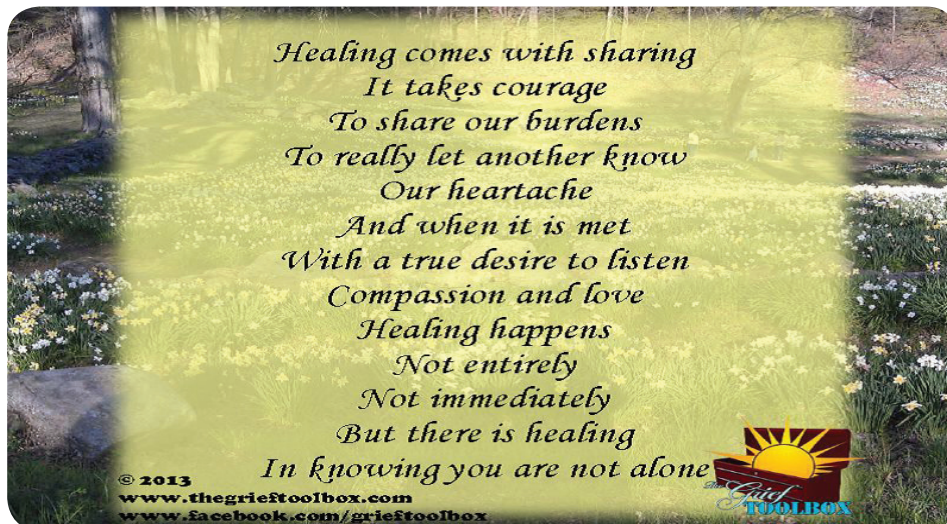
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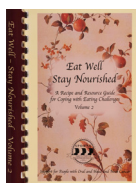


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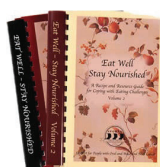
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## **Cozy Comfort Foods from “Eat Well Stay Nourished A Recipe and Resource Guide For Coping With Eating Challenges”**

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

### ***Fabulous Broccoli Cheese Soup (from Volume One)***

2 to 3 medium large stalks fresh broccoli, chopped finely  
 ½ c. finely chopped onion  
 ½ c. finely diced carrots  
 ½ c. finely diced celery  
 ¼ c. butter  
 ½ c. flour  
 1 qt. half and half  
 4 c. chicken broth  
 dash of salt  
 dash of paprika  
 1 c. cubed cheddar or American cheese



Chop broccoli, celery, onions, carrots in food processor or very finely. Bring broth to a boil in pot and add vegetables, except onions. Return to a boil and simmer 15 minutes. In a 5 quart pot, melt butter and add onion, cooking until tender. Blend in flour, stirring constantly until smooth. Add half and half. Add ingredients from broccoli pot. Cook and stir until thick and bubbly. Lower heat. Add cheese. *Yields 8 – 8 oz. servings. 392 calories/serving.*

*~ Linda F., Virginia*

### ***Noodle Kugel (from Volume Two)***

½ lb. wide egg noodles  
 ½ stick butter, melted  
 1 lb. regular cottage cheese  
 2 c. regular sour cream  
 1/2 c. sugar  
 6 whole eggs  
 1 tsp. ground cinnamon (optional if you have trouble with spices)  
 ½ c. raisins or 1 can (8 oz.) crushed pineapple with juice drained (based on taste or availability, you can add just one or both)



Boil the noodles in salted water for about 4 minutes. Strain water and hold aside. In a large mixing bowl, combine noodles with remaining ingredients and pour into greased 9 x 13 baking dish. Bake until custard is set and top is golden brown – about 45 minutes. If you want a softer crust, cover with aluminum foil to keep top from browning. Keeps well covered and refrigerated. *Serves 8. 456 calories/serving.*

*~ Jeff K., New York*



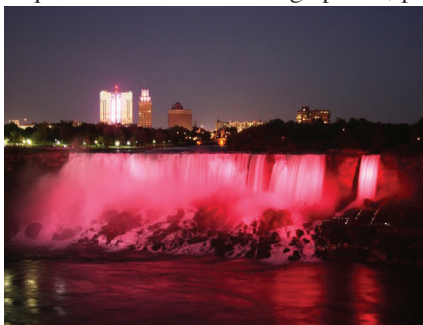
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## April Awareness is About to Arrive!

April is Oral, Head and Neck Cancer Awareness Month, as designated by SPOHNC. The entire month is designated in honor of SPOHNC's Founder, Nancy Leupold, who was diagnosed in April of 1991.

SPOHNC has heard of quite a few events that are happening, or already have, to raise awareness. There have been recognition and appreciation events, exercise classes, taste events and more. Once again this year, SPOHNC has been able to arrange for the lighting of Niagara Falls in SPOHNC colors. This special lighting was arranged for compliments of The Niagara Falls Illumination Board and is taking place on April 3<sup>rd</sup>, from 10 to 10:15pm. If you're



in the area, check it out - and if not, you can always see it live via the Niagara Falls webcam at [http://www.niagarafallslive.com/niagara\\_falls\\_webcam.htm](http://www.niagarafallslive.com/niagara_falls_webcam.htm).

If you attend a SPOHNC Chapter support group meeting and you're doing something special, please be sure to let us know. We'd like to help you promote your event and raises awareness. If you attend an event and have photos or a story to tell, please send it to us at [info@spohnc.org](mailto:info@spohnc.org). Whatever you're doing and however you're participating, we want you to let us know. We all need to raise awareness, share information and inspire hope!

Birthdays are special for our SPOHNC family members. They are a time to celebrate life, happiness and especially, good health... precious gifts.

SPOHNC's Chapter Support groups share a camaraderie like no other, and celebrate and remember important milestones and days. Two attendees of our Terre Haute, Indiana SPOHNC Chapter recently celebrated some happy occasions. Happy Birthday to Jon Ramos, who celebrated a birthday on March 16<sup>th</sup>, and Bob Thomas, who celebrates a birthday on March 30<sup>th</sup>! SPOHNC wishes you a year full of health, happiness and joy.

Our SPOHNC Chapters would not function without the dedication of our Chapter Facilitators. SPOHNC's Greenville, South Carolina Chapter Facilitators are Bill and Linda, known as Team Clyde. Survivor, Bill, and caregiver, Linda, have become an integral part of the SPOHNC family, truly giving their all to support those who come to them seeking hope. SPOHNC heard that



Bill just celebrated his special day - on March 12<sup>th</sup>! Never one to do things the same old way, Linda surprised Bill a few days early with a giant almost-birthday version of his favorite pastry at their favorite bakery. SPOHNC wishes you a year of great things, relaxation and lots of laughter! Happy Birthday Bill!!

*From SPOHNC Executive Director, Mary Ann Caputo -*

March is a very special month for SPOHNC. Two of its leading ladies are celebrating their birthdays! It's our privilege to wish Nancy Leupold, Survivor, Founder, President Emeritus and Chris Leonardis, Outreach Administrator/Editor a very Happy Birthday. It goes without saying that our President, Nancy Leupold and our esteemed colleague, Chris, possess many qualities that inspire others, giving them hope and the desire to overcome many challenges after being diagnosed with oral, head and neck cancer.

Twenty seven years ago, Nancy saw a need and had a deep desire to help others who were seeking support, information and help along their cancer journey.

At SPOHNC, we celebrate the birthday of a woman who



remains near and dear to our SPOHNC heart - Happy Birthday Nancy! We wish you love, happiness and lots of yummy goodies on your birthday!

Chris Leonardis has given SPOHNC her invaluable creativity in bringing our audience a newsletter filled with state of the art information, sharing stories that will melt your heart and encourage one to strive for the best that life can offer. She is part of SPOHNC's team that works diligently to make sure that each person who contacts SPOHNC receives the kindness, caring and information they need to go forward. She communicates with callers in a warm and consoling way and her genuine sincerity brings calmness to all who she speaks with and helps to support through SPOHNC's many programs. Chris - SPOHNC wishes you a birthday celebration that will warm your heart and bring you many blessings. You are a blessing to SPOHNC!



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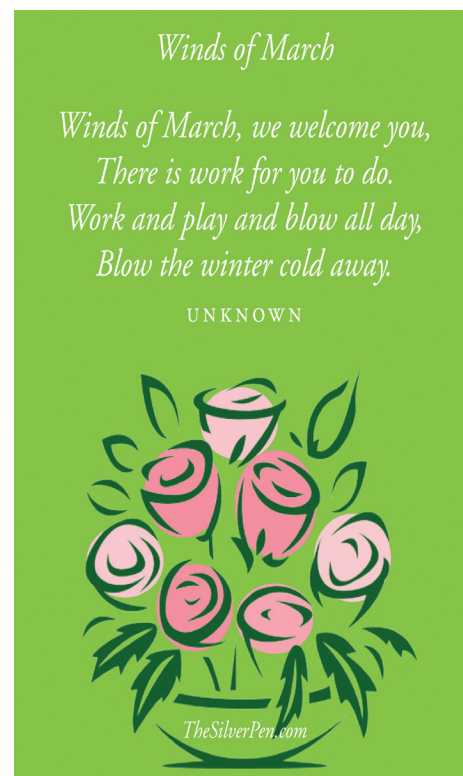
## Thank Your Social Worker in March

National Professional Social Work Month is an opportunity for social workers across the country to turn the spotlight on the profession and highlight the important contributions they make to society. We celebrate the contributions of social workers during National Social Work Month in March.

Our nation's more than 650,000 social workers have amazing tenacity and talent. They confront some of the most challenging issues facing individuals, families, communities and society and forge solutions that help people reach their full potential and make our nation a better place to live.

Join SPOHNC in thanking all of those social workers who assist newly diagnosed patients and survivors. Social workers are SPOHNC Chapter Facilitators and Co-Facilitators. They are the professionals who help you to find the assistance you need. Many social workers have helped connect you with SPOHNC, and our programs and services of support.

Social workers...Your SPOHNC family expresses gratitude and appreciation to each of you for your tireless dedication, commitment to helping others and for all that you do each and every day for those who have been affected by the diagnosis and treatment of oral, head and neck cancer. Thank you!!



## Head and Neck Cancer News

### Study provides new guidelines for assessing severity of head and neck cancers

Jan. 24, 2018 - Cedars-Sinai investigators have developed a new, more accurate set of guidelines for assessing the severity of head and neck cancers and predicting patient survival.

The new guidelines, outlined in a study recently published in the *Journal of Clinical Oncology*, center around counting the number of malignant lymph nodes found in each patient.

"The greater the number of malignant lymph nodes, the less favorable the patients' chances of survival," said Allen S. Ho, MD. Ho is director of the Head and Neck Program at the Samuel Oschin Comprehensive Cancer Institute at Cedars-Sinai and lead author of the study. "This new approach could dramatically simplify staging systems."

For decades, doctors have determined the stage and predicted the progression of head and neck cancers based primarily on nodal size, location and how far the cancer has spread beyond the lymph nodes, but they have given less importance to the number of cancerous nodes. As a result, staging and treatment recommendations, based on current national guidelines, "are the same whether a patient has two or 20 positive lymph nodes," said Zachary

S. Zumsteg, MD, assistant professor of Radiation Oncology at Cedars-Sinai and the study's senior author.

With the new system, based on the number of cancerous lymph nodes, patients are separated into similarly sized groups with distinct outcomes, Zumsteg said. "Our study demonstrated a better way to assess cancer severity, which will improve our ability to predict outcomes and give patients more personalized treatment."

The Cedars-Sinai study involved reviewing data of 14,554 U.S. patients identified in the National Cancer Database who were treated for squamous cell carcinoma of the oral cavity (mouth, gum and tongue) between 2004 and 2013.

The data showed that an increased risk of death was associated with each additional cancerous lymph node found. The investigators concluded that the number of cancerous lymph nodes is a predominant, independent factor associated with death in those patients. The study also identified an ultra-high-

risk group of patients with five or more cancerous lymph nodes.

Head and neck cancers occur in the lips, tongue, gums, bottom of the mouth, throat, larynx, nasal cavity and salivary glands. About 63,000 people developed head and neck cancers in the U.S. in 2017. More than 13,000 deaths from those cancers occurred during that period, according to the American Society of Clinical Oncology.

"Although considering the number of cancerous lymph nodes in staging is a simple concept that many head and neck cancer specialists have assumed to be true for years, data has been limited until now," Zumsteg said. The study authors said they hope that, based on the new data, the number of positive nodes in staging will now be incorporated into clinical practice.

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

*~ Jeff H.*

**Connect with SPOHNC's "group" on Facebook**

## Head and Neck Cancer News

### Antibiotics may impact cancer treatment efficacy

March 3, 2018 - Antibiotic use is known to have a near-immediate impact on our gut microbiota and long-term use may leave us drug resistant and vulnerable to infection. Now there is mounting laboratory evidence that in the increasingly complex, targeted treatment of cancer, judicious use of antibiotics also is needed to ensure these infection fighters don't have the unintended consequence of also hampering cancer treatment, scientists report.

Any negative impact of antibiotics on cancer treatment appears to go back to the gut and to whether the microbiota is needed to help activate the T cells driving treatment response, says Dr. Gang Zhou, immunologist at the Georgia Cancer Center and the Department of Biochemistry and Molecular Biology at the Medical College of Georgia at Augusta University.

"It likely depends on what types of therapy physicians are giving to patients and how often they also are giving them antibiotics," says Zhou, corresponding author of the study in the journal *Oncotarget*. They have some of the first evidence that in some of the newest therapies, the effect of antibiotics is definitely mixed. Infections are typically the biggest complication of chemotherapy, and antibiotics are commonly prescribed to prevent and treat them.

"We give a lot of medications to prevent infections," says Dr. Locke Bryan, hematologist/oncologist at the Georgia Cancer Center and MCG. "White blood cell counts can go so low that you have no defense against bacteria, and that overwhelming infection can be lethal," says Bryan, a study co-author.

In this high-stakes arena, where chemotherapy is increasingly packaged with newer immunotherapies, Bryan, Zhou and their colleagues have more evidence that antibiotics' impact on the microbiota can mean that T cells, key players of the immune response, are less effective and some therapies might be too. They report that antibiotic use appears to have a mixed impact on an emerging immunotherapy called adoptive T-cell therapy, in which a patient's T cells are altered in a variety of ways to better fight cancer. They found that one of the newest of these -- CAR T-cell

therapy -- is not affected by antibiotics, likely because it is not so reliant on the innate immune system. "These infused T cells can pretty much act on their own to kill cancer cells," Zhou says.

With this approach, physicians retrieve T cells from a patient's blood, engineer them to express a tumor-finding receptor -- called chimeric antigen receptor, or CAR -- and give them back to the patient. These patients typically will receive a conditioning chemotherapy regimen, which often includes the common agent cyclophosphamide, or CTX, to intentionally wipe out some of their normal T cells and make room for the engineered super-fighters. This emerging treatment is often used in patients who have failed multiple other treatments, including chemotherapy.

Even long-term antibiotic use does not seem to hinder the efficacy of CAR T-cell therapy against systemic lymphoma in their animal model. While they could see the impact of antibiotics on the microbiota, mice with CAR T-cell therapy continued to respond well to cancer treatment. But the efficacy of another mode of adoptive T-cell therapy was impacted. This model mimics therapy in which receptors that target the patient's tumor are put onto their T cells. In this case, the researchers transferred tumor-specific CD4+T cells to treat mice with colorectal cancer.

One key difference here is that, unlike the CAR T-cell therapy, these engineered T cells still need help from the innate immune system to fight the tumor, now that they can better target it, Zhou says. Mice with colorectal cancers that did not receive antibiotics were cured after being treated with the chemotherapy CTX followed by CD4+T-cell therapy. However, with antibiotics on board, this curative effect was lost in three out of five mice three weeks after treatment.

Their studies also confirmed that antibiotic use impacts the efficacy of the widely used CTX, when it's used alone, in this case to treat B-cell lymphoma. In addition to directly killing rapidly dividing cancer cells, CTX gets the attention and help of endogenous T cells, and antibiotics reduced that T-cell response, the scientists

report.

Their findings in lab animals confirmed the recent work of others that the altered intestinal microbiota impacts CTX's ability to fight sarcoma, a rare cancer of our connective tissue. Bigger picture, it suggests that some chemotherapy regimens rely on the gut bacteria to stir the immune system to fight cancer, the scientists write.

"It is clear in animal models that if you wipe out the intestinal microbiota, like you do with antibiotics, it will attenuate the chemotherapy efficacy," says Zhou. "There is also emerging clinical evidence showing that for CTX-based chemotherapy, some patients who also get antibiotics for a longer period of time, seem to have less optimal outcomes."

Human studies are needed to see whether antibiotics affect the outcomes of adoptive T-cell therapy and to give clinicians and their patients better information about how best to maneuver treatment, Zhou notes.

The microbiota is comprised of trillions of bacteria, viruses and fungi and the biggest population resides in our gut, where they help us digest food and protect us from other invaders. Anyone who has taken an antibiotic also knows it can wreak havoc with the gut, causing severe diarrhea and other discomfort as it alters the natural -- and healthful -- complement of our microbiota.

While even a single course of antibiotics has been shown to disrupt the microbiota in humans, Zhou has shown in mice that it is protracted use that likely also impacts the immune response. And, when mice, at least, have a weakened immune system their microbiota literally looks different and there is evidence that antibiotics suppress their immune response.

Even with antibiotics out of the equation, there can be conflicting crosstalk between chemotherapy and immunotherapy. If/when chemotherapy hampers the immune response it could obviously impact the efficacy of some immunotherapies. So scientists and clinicians alike also are trying to figure out how best to combine these different therapies, to achieve optimal synergy.

*The research was funded by the National Institutes of Health and an American Cancer Society Research Scholar Grant.*



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*"Coming to the meetings gives me a  
sense of accomplishment – to see how  
all of my friends are doing and making  
progress"*

*~ Ray G.*



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