

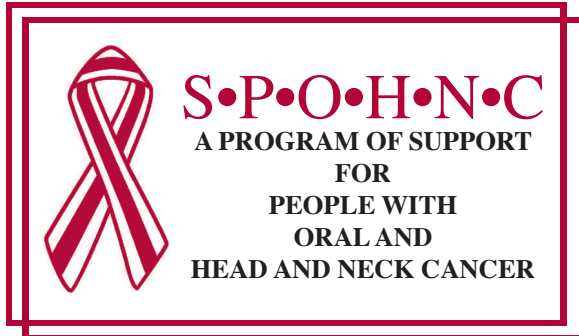
NEWS FROM S•P•O•H•N•C



VOL. 29 NO. 2

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

OCTOBER 2019



Less Intensive Treatment May Be Possible For Some Patients with HPV-Associated Head and Neck Cancer

Katharine Price, MD

In my experience as a head and neck medical oncologist, fear of long-term side effects of cancer treatment is second only to the fear of cancer recurrence. Treating the head and neck region using surgery, radiation, and chemotherapy, can result in significant permanent side effects including dry mouth, altered or absent taste, difficulty swallowing, and chronic pain. Until recent



years, the trend in the treatment of head and neck cancer was to intensify treatment to try and improve outcomes for patients – alter the radiation schedule, add chemotherapy, or combine multiple chemotherapy drugs together. Although there were some modest improvements in cancer outcomes and survival, it was at the cost of more patients experiencing more intense and

permanent sequelae of cancer treatment.

Approximately 10-15 years ago, researchers noted that the human papillomavirus (HPV) was present in an increasing number of cancers of the oropharynx (tonsil and base of tongue). The increase was quite dramatic – in the 1980's only 16% of cancers were associated with HPV, but in the 2000's this percentage had risen to greater than 70%! Subsequent research showed that HPV was causing cancers of the oropharynx, and that the

chance of long-term survival or cure with standard treatments was significantly better.

Once HPV was established as a cause of head and neck cancer, it became evident that HPV-associated cancer was truly a different disease than cancer of the head and neck caused by smoking and alcohol use. HPV cancers often occur in patients at a younger age, and frequently in patients who have never smoked. HPV cancers are much more common in men (8 times more common), and most people who develop a cancer caused by HPV are healthy without significant medical conditions. On a molecular level, HPV cancers have fewer mutations (alterations in tumor genetic make-up) than those caused by smoking. And notably, HPV cancers appear to be more sensitive to standard cancer therapies including radiation and chemotherapy.

The rising number of HPV cancers in younger, healthier patients means that there are more long-term survivors of head and neck cancer, and that these individuals will potentially live decades with the side effects of their cancer therapy. This new reality has driven a wave of research in head and neck oncology looking to change treatment paradigms for HPV-associated head and neck cancer with two fundamental goals: preserve the high cure rates and minimize treatment-related long-term side effects.

Long-term, permanent side effects of treatment for HPV oropharynx cancer is primarily driven by the extent (radiation field) and dose of the radiation therapy that is administered. The resurgence in recent years of minimally-invasive, robotic surgery to remove oropharynx cancer has minimized the long-term side effects of surgery and allows for a lesser dose of radiation therapy after surgery. In 2013 our multidisciplinary cancer care team - head and neck surgeons, radiation oncologists, medical oncologists, swallow therapists, and dentists - at Mayo Clinic began testing a new approach to treating patients with human papillomavirus (HPV)-related oropharynx cancer that allowed patients to receive a significantly lower dose of radiation than what is typically given with standard radiation regimens. Because the treatment was experimental, it was given in the setting of a research study, or clinical trial. The study enrolled 80 patients between September 2013 and June 2016 at the Mayo Clinics in Rochester, Minnesota, and Scottsdale, Arizona. All patients were diagnosed with a squamous cell cancer of the tonsil or base of tongue that was associated with HPV and was confined to the head and neck region, and had never smoked or had only smoked for a short period of time in the past. All patients first underwent surgery to remove the cancer from the tonsil or back of tongue and the lymph nodes in the neck. Most of the surgeries were performed through the mouth with the use of a robot (transoral robotic surgery), allowing for complete removal of the cancer with minimal long-term consequences.

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Chris Leonardis

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Approximately one month after surgery, patients then had two weeks of radiation therapy given twice daily, Monday through Friday (10 total days on treatment, 20 total radiation treatments) along with a small dose of chemotherapy each week (total 2 doses of chemotherapy). The patients were divided into two groups based on pathologic risk factors (microscopic features that contribute to a risk of cancer recurrence) which determined their total radiation dose. Cohort A consisted of patients with one or more intermediate risk factors on pathologic analysis including lymphovascular space invasion, perineural invasion, ≥2 lymph nodes involved with cancer, any single lymph node containing cancer > 3 cm, or a primary tumor > 4 cm. Patients in Cohort A received a total radiation dose of 30 Gy along with a small dose of chemotherapy (docetaxel) each week. Cohort B included patients with the high-risk pathologic feature of extranodal extension (microscopic extension of cancer cells outside the lymph node capsule) and these patients received a total dose of radiation of 36 Gy along with the same chemotherapy.

How does this experimental regimen compare with standard treatment for oropharynx cancer? There are two widely accepted standard treatment options for HPV oropharynx cancer that is confined to the head and neck region, and thus potentially curable. The first option involves seven consecutive weeks of daily radiation therapy (Monday through Friday) to a total dose of 70 Gy along with high-dose chemotherapy, typically cisplatin. The second option entails having surgery first to remove the cancer in the throat and the lymph nodes in the neck followed by six consecutive weeks of daily radiation therapy (Monday through Friday) to a total dose of 60 Gy with or without chemotherapy (also cisplatin). In both of these standard treatment pathways, patients receive a significant dose of radiation therapy and require months to recover from the short-term toxicities of treatment. The typical progression of radiation-related side effects include dry mouth and absent taste in the first 1-2 weeks of radiation followed by progressively more intense mouth sores (mucositis) and thick saliva for the remainder of treatment. Collectively, these side effects make it difficult to keep eating and drinking, and a significant number of patients – approximately 20% in modern studies - require a feeding tube in the stomach (PEG) to safely complete treatment. Side effects gradually lessen over the weeks to months that follow treatment, although improvement is slow but steady. Most patients will return to work approximately 3 months after the completion of therapy and most patients need a full year before they feel almost back to their baseline level of functioning. Cisplatin chemotherapy can cause short-term side effects of nausea, decreased blood counts, electrolyte disturbances, ringing in the ear, and injury to the kidneys.

In contrast, our study with a shortened course of radiation (half of standard dosing) and low-dose chemotherapy after surgery allowed for less short-term toxicity and a faster recovery than seen with standard treatment. Effectively, the twice daily radiation therapy for two weeks was half the total dose of radiation therapy compared with the standard six weeks of radiation after surgery. In our study, patients generally felt well while they were going through the two weeks of treatment, but then quickly developed mouth sores and thick saliva at the end of treatment which was intensive for 1-2 weeks and then rapidly improved. As a result, only one patient required a feeding tube in the stomach to get through treatment safely, and

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most patients were back to work and eating a full diet by one month post completion of radiation therapy. We chose to substitute the chemotherapy docetaxel for cisplatin as it does not have significant short or long-term complications in small doses as given in the experimental treatment. The only notable side effect we saw during treatment was an allergic reaction during the docetaxel infusion in a handful of patient which was easily treatable with medications such as diphenhydramine (Benadryl).

Not only are short-term (acute) toxicities improved with the de-intensified treatment, but long-term toxicity rates and quality-of-life are as well. Historically, for standard treatment regimens of radiation and chemotherapy, the rates of significant long-term side effects (grade 3 or 4) are high (10-80%) depending on the study. In our study, there were no grade 3 or 4 toxicities seen beyond 3 months. The most frequent long-term grade 2 toxicities seen were dry mouth and mild swallowing dysfunction. Grade 2 (moderate) and grade 3 (severe) toxicity rates before radiation and at 1 and 2 years after radiation were 11.4% and 2.5%, 1.4% and 0.0%, and 6.7% and 0.0%, respectively. The most frequent grade 2 events were dysphagia, xerostomia, and oral mucositis. There were no long-term complications seen from the chemotherapy on the study. Quality of life was measured by several well-established tools (surveys) and showed improvement over the year following treatment compared to baseline measurements done after surgery and before radiation. The only quality of life measurement that showed a temporary decline was a tool looking at quality of life related to dry mouth, which declined slightly immediately after radiation therapy and then recovered.

We found that measurements of efficacy including recurrence rates and survival rates were comparable to standard treatment regimens. Patients were followed for an average of three years before study results were reported. For the study patients as a whole, the local-regional control rate at two years was 96%, meaning that 96% of patients had no evidence of cancer in the head and neck two years after completion of treatment. When broken down by cohorts, patients in Cohort A (intermediate risk) had 100% local-regional control (no recurrences

in the head and neck), and patients in Cohort B (high risk) had a local-regional control rate of 93%. For the study as a whole, 95% of patients were alive at two years with no evidence of distant metastases (spread of cancer outside the head and neck). As anticipated, more recurrences were seen in the high risk group than in the intermediate risk group. One patient in Cohort A (2.8%) and nine patients in Cohort B (20.9%) experienced some type of disease recurrence (local-regional or distant).

It is well-established that a cancer diagnosis and cancer treatment is a significant financial stressor for patients and their families. As part of the study, we conducted a financial analysis of the shortened treatment compared with standard of care therapy. Total average treatment cost for patients receiving the shortened treatment was \$45,884, of which \$17,791 comprised chemotherapy and radiation therapy charges and \$28,093 were surgical or imaging/examination charges. Average total charge for patients receiving standard 6-week adjuvant therapy during this same time period was \$57,845, of which \$26,603 comprised chemotherapy and radiation therapy charges and \$31,242 were surgical imaging/examination charges. This study had a 33% reduction in radiation therapy cost and a 21% reduction in total treatment cost compared with standard adjuvant therapy. As health care costs continue to grow, it is important to look for treatment options that can lessen financial toxicity for patients with cancer and their families.

The 2-year results from our study demonstrated the feasibility and promise of this treatment regimen for patients with a minimal smoking history and HPV-associated oropharynx cancer. In particular, this appears to be a promising regimen for patients with HPV oropharynx cancer with intermediate risk factors after surgery (Cohort A). Currently, our Mayo group is conducting a larger follow-up study that is a head-to-head comparison of our two week post-surgical regimen to the standard of care post-surgical regimen (6 weeks of daily radiation therapy with or without chemotherapy). This study is randomized to allow a clean, objective comparison between these two treatments.

Our hope is that our ongoing larger study will help to define which patients can

safely receive this de-intensified regimen and eventually to allow such patients to receive the shorter regimen as standard treatment outside of a clinical trial. For now, however, our shortened regimen of twice-daily radiation and weekly chemotherapy after surgery is still considered experimental and can only be given in the setting of a clinical trial.

The future is looking bright for the treatment of HPV-associated oropharynx cancer. Our research effort is only one of many different approaches that are being studied across the country and the world to minimize how much treatment patients with HPV head and neck cancers require to cure the disease and maintain quality of life and function. The greatest joy that we have as doctors and researchers is seeing our patients back years later with no evidence of cancer and enjoying all that life has to offer. We learn so much from each and every patient, and extend tremendous gratitude to all of our patients who participated in the trial to help redefine the future for head and neck cancer.

My final parting thought - from oncologist to patient - is to PLEASE encourage all family members and friends to vaccinate their children and young adults against HPV. These are preventable cancers, and prevention is truly the ultimate and least toxic of all cancer treatments.

Reference: 1Ma DJ, Price KA, Moore EJ, Patel SH, et al. Phase II Evaluation of Aggressive Dose De-Escalation for Adjuvant Chemoradiotherapy in Human Papillomavirus-Associated Oropharynx Squamous Cell Carcinoma. *J Clin Oncol* 37:1909-1918.

Editors Note: Katharine A. Price, M.D., is Associate Professor of Oncology and Chair of the Head and Neck Cancer Tumor Group in the Division of Medical Oncology at Mayo Clinic in Rochester, Minnesota. Dr. Price is a Connecticut native who completed undergraduate studies in French at Harvard University before attending medical school and internal medicine residency at Mayo Clinic in Rochester, Minnesota. During residency training she developed an interest in head and neck cancer. She completed her oncology training at Memorial Sloan-Kettering Cancer Center in New York, New York, before returning to Mayo Clinic to join the staff in 2010. Since that time she has focused her clinical practice and research on the care and treatment of patients with head and neck cancer.

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Golfing for Good at the 4th Annual Rick Agee Memorial Golf Tournament

On June 22nd it was a beautiful sunny, Summer day – the kind of day that Kerry Agee’s brother, Rick, would have loved. It was also the perfect day for some fun and relaxation on the links at the Cliffs Resort on Possum Kingdom Lake, in Graford, Texas, and a tournament to honor the memory of a man with a heart as big as Texas - Rick Agee.

The golf tournament has been an annual happening for the Agee family and friends since Kerry and Rick were in their 20’s. Since Rick’s passing in 2015, his family and friends have continued the tradition of the annual tournament, and have donated the proceeds of the event to SPOHNC to honor and pay tribute to one of SPOHNC’s fondest friends, Rick Agee. The day has become increasingly popular among Rick’s family and friends. It’s a chance to come together, and share fond memories of that “larger than life” presence that was so familiar to so many – Rick.

Each year, the winning team gets a “trophy” which they keep for the year until the next tournament. The trophy is one of Rick’s hats that he wore for one of the tournaments in the past. The winning team each year signs the hat and keeps it for a year, then brings it back to the tournament the following year.

Pictured here is John Agee presenting the hat to winning team member, Seth Muhlstein, who accepted the trophy on behalf of his team - Jeff Frasier, Greg Kilpin, Adrian Muhlstein and Seth. Congratulations to the winners, and to all of the tournament participants this year.



A dear and special friend to SPOHNC, many will remember Rick as the one who held two *Skate for SPOHNC* events in sunny Texas, to benefit SPOHNC. In the SPOHNC national office in New York, we remember Rick as the fun-loving man who just showed up at our door one day (in New York!), and greeted us with a “Hellooooo SPOHNC chicks!” as he opened the door for his surprise visit. His exuberance and cheerfulness was overwhelming. He was quite a guy!

SPOHNC wishes to thank Kerry, and the entire Agee family, as well as Rick’s friends, and each of the supporters of

the day, for your continued dedication to our mission. Special thanks go out to the tournament friends and donors below:

Kerry and Janie Agee, Ben & Martha Agee, John & Cynthia Agee, Southwest Nursery, Rob & Ceneria Helbing, Jay & Judee Houston, Bill & Evett Smith, James & Terri Mckee, Dave & Kelene Totze, Mark & Tina Dotson, Greg Kilpin, Steve Lewis, Joe Longino, Frank Larocca, Steve DeFoe, Dave Dumais, Jamie Klein, Fantastic Moves, Neugent Helbing, E.L. Biggerstaff, The Plant Factory, Floratech, Inc.

We think of Rick so very often, and his photos grace the walls of our office. We share fond memories and stories about Rick all the time. We were honored to share the times that we did with such an amazing man, and we still miss him every single day.



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packed with the latest product information to help with the side effects of treatment. What helps dry mouth? What helps with neck pain? What relieves itchy skin? The Product Directory has the answers.

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- SPOHNC has more than 100 CHAPTER Support Groups, as well as a National Survivor Volunteer Network, connecting patients and survivors. More than 225

survivor and caregiver volunteers are ready and willing to serve as a mentor to a newly diagnosed patient or caregiver.

- Access to additional resources through direct contact with SPOHNC’s Outreach Staff.
- Insider information about special programs and resources.



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Chapter Facilitator News

Survivor of HPV - Related Neck Cancer Shares 6 Tips for Others in Treatment

Patrice Saurman - SPOHNC Hershey, PA Chapter Facilitator

Editors Note: It was SPOHNC's pleasure to facilitate this connection between Stephanie and Patrice upon being contacted by the writer. This article was reprinted with permission from HealthCentral.com and Stephanie Stephens, M.A., health journalist, Jan. 24, 2019. For more on the SPOHNC Penn State Health Milton S. Hershey Medical Center support group, please call SPOHNC at 1-800-377-0928 or e-mail us at info@spohnc.org



Sometimes life deals you a hand you just never expected. In Patrice Saurman's case, this came in the form of a neck cancer.

Patrice, 67, of Camp Hill, Pennsylvania, is a registered nurse who uses both her medical expertise and her personal experience with cancer to be a supporter, patient advocate, and friend to others with the same diagnosis. She is nurse facilitator for Penn State Hershey's Head and Neck Cancer Support Group, a local chapter of the national organization Support for People with Oral and Head and Neck Cancer (SPOHNC).

HealthCentral spoke with the head and neck cancer survivor of 10 years about her cancer journey and her tips for others going through similar diagnoses.

HealthCentral (HC): *What was your first reaction to your diagnosis in 2007?*

Patrice: My husband, Lee, and I were quite alarmed when we found a raised lump on the side of my neck that I hadn't noticed the day before. I was referred to an oncology surgeon at Penn State Health.

After what would hopefully be just an incisional biopsy, we were stunned when to

learn the mass was cancerous. The surgeon was certain he had gotten all of it. I came out of surgery with 32 lymph nodes removed, a modified radical neck dissection, and a large incision from behind my left ear to the midline of my neck. It was what my doctor considered an unknown primary tumor, meaning the primary source was unknown, but that he suspected it may have originated in my tonsils. I had a second surgery to have them removed as a precaution, but no cancer was found. It remains "the unknown primary."

HC: *What connection did your neck cancer have to the human papillomavirus (HPV)?*

Patrice: We do know from the pathology report that the HPV was present

[in the tumor]. Statistics show that HPV, a sexually transmitted disease, is thought to cause 70 percent of oropharyngeal, or throat and mouth cancers, in the United States. Over 20 million Americans carry this virus.

Gardasil 9, the HPV vaccine, is now approved by the FDA for use in males and females ages 9 through 45. It is the only vaccine that prevents over 90 percent of possible HPV-related cancers, protecting people against nine strains of the virus responsible for the majority of these cancers and diseases. Due to an alarming rise in the number of people infected, it has now reached epidemic proportions.

I'm very concerned that many parents who have never even heard of HPV or know very little about it have decided that they don't want their children vaccinated. I don't think they understand that this virus can remain dormant in the body for 20 years or more before striking. I cannot stress enough the importance of parents learning more, talking to their family doctor, and hopefully reconsidering. We want our children to be healthy not just for today, but to remain healthy well into adulthood. They are the future of tomorrow.

HC: *What was the most challenging part of treatment for you?*

Patrice: The chemotherapy and radiation: I was supposed to have three rounds of chemo with Cysplatin, but I could only tolerate two. I was also supposed to have 30 rounds of radiation therapy, but only had 25. My biggest problem, though, was what I called "mucous mouth." Radiation destroys salivary glands, causing a lack of saliva. This results in a thick, mucousy saliva that coats the mouth and tongue and is almost impossible to get rid of for more than a few seconds. I spent hours in the bathroom trying to clear my mouth, rinsing and rinsing to get rid of these slimy secretions, only to have it return in less than a minute. This lasted for months and caused me a great deal of anxiety.

HC: *What are the most important things you learned during treatment?*

Patrice: Don't isolate! Many people have never heard of head and neck cancer and may back away from you because they continued on p. 6

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don't know what to say. Reach out to them! Many patients become very self-conscious and tend to withdraw because of serious side effects they may be dealing with. It's so important to know you are not alone. It took me six months to work up the courage to attend a meeting. When I finally did, I found a group of people who knew exactly what I had gone through because they had gone through the same. Bonds are often formed with one another because we've all shared so much. Suddenly, I didn't feel so alone anymore. I had support, and I learned that I was a lot stronger than I thought I was. I began to heal.



HC: *What are some of your best tips for self-care?*

Patrice: I have six tips I hope will help someone:

1. **Keep a positive attitude:** Surround yourself with positive people, places, and activities — whatever makes you happy. I spent a lot of time with our Silky terriers, Lexi and her daughter, Lola. They've been so devoted to me, right by my side the entire two months I was in bed. I always love their company.
2. **Keep up with any hobbies and interests you may have:** I love reading and writing. I've written a novel and am in the middle of writing another. I journal when something bothers me or when I want to preserve a memory. I enjoy making natural skin-care products. Taking a drive or going for a ride in the car always lightens my spirits.
3. **Volunteer:** Help someone in need. Make someone smile. It will help take your mind off your troubles and make you realize that you're not the only one

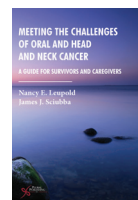
who struggles. In helping someone, you're helping yourself. What Lee and I have learned is that there's more joy in the act of giving than there is in receiving. As my caregiver and a member of the group, he's been very supportive and involved with not just me, but with the group as well, from the very beginning

4. **Accept when people say, "Let me know if there's anything I can do for you":** If someone says they would like to help with "anything," tell them specifically what your needs are. Maybe they could babysit, or run errands, or take you shopping, or prepare a meal for your family, give you a ride to an appointment, or just stop by and visit. If you just say "OK," chances are you won't contact or hear from them. They asked. Don't be shy. Tell them!
5. **Don't worry about your hair falling out:** It will grow back! In the meantime, go shopping when you're feeling up to it. There are a lot of nice wigs and fun hats that are sure to lift your spirits. Or you can be daring and just go hair-free!
6. **Don't isolate yourself:** Find a support group and start attending, even before you start treatment. There is so much to learn. In our group, we welcome newcomers and encourage them to share and we also share our stories and experiences. Members have a wealth of information you may never learn in your doctor's office. We often have interesting and informative speakers: a lymphedema specialist, physical therapist, dietician, social worker, speech pathologist, surgeon, audiologist, or oncology radiologist. Newcomers are often better informed, better adjusted, and more confident. I wish I had joined much sooner!

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~ Else S.

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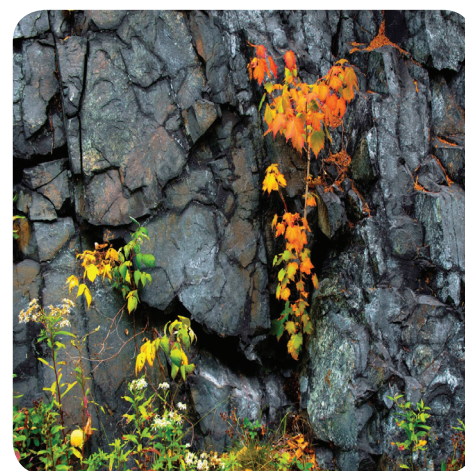


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**Recipes from
“Eat Well Stay Nourished A Recipe and Resource Guide
For Coping With Eating Challenges”**

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

Sweet Potato Rumba (from Volume One)

4 c. hot boiled sweet potatoes or yams, peeled
¼ c. melted butter or margarine
½ c. heavy cream
½ tsp. ground nutmeg
½ tsp. salt
¼ c. sugar
1 tsp. rum extract (optional)
1 Tbsp. melted butter or margarine
1 Tbsp. grated orange rind (optional)



Preheat oven to 400 degrees. Press sweet potatoes or yams through food mill or ricer. Add ¼ c. butter or margarine, cream, nutmeg, salt, sugar and rum extract. Beat until fluffy. Turn into 1 quart casserole dish. Drizzle with 1 tablespoon melted butter or margarine. Sprinkle with orange rind. Bake 30 minutes or until lightly brown. Yields 6 (5 ounce) servings. 264 calories per serving.

~ Member of PTRP, NY

Easy, Healthy Apple “Bake” (from Volume Two)

2 Golden Delicious apples
1 Tbsp coconut oil
Cinnamon to taste
½ c. quick oats
1 Tbsp. honey

Core and slice apples. Place in microwaveable dish. Heat coconut oil in microwave for 30 seconds or until melted. Drizzle over apples. Add honey, cinnamon and quick cook oats over apple mixture. Heat in microwave for 5 minutes until soft. Enjoy. Serves 2. 264 calories per serving.



~ Hillary M., NY



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Time for Sharing...My Cancer Journey

My cancer journey began in October, 2002. For better and worse, this has been a long journey - one which has involved some long term sequelae that I will share below. But first, my case history.

I was diagnosed and treated at the University of Michigan. I was pretty much symptom-free aside from a double clutch swallow if I had an icy cold drink. I did have a swollen lymph gland that provoked some concern by my primary care doc who referred me to an ENT.

My diagnosis was T3N2 base of tongue squamous cell carcinoma. I was 46, married, two daughters ages 11 and 8, and in excellent health. I was also the co-founder of a start-up company and responsible for 14 employees.

The timing of the diagnosis was unfortunate, not that there is ever a good

time for this kind of news. In our case this was mid November, shortly before we were to leave on a family 'trip of a lifetime' to the Maho Bay Ecoresort in St. John in the U.S. Virgin Islands for Thanksgiving week. I was quickly scheduled for an after midnight MRI, and the day before the flight was the fine needle aspiration. That is not a procedure I recommend having at a teaching hospital.

The 'tumor board' met while we were away. We returned to learn the treatment protocol. Surgery was ruled out. 70 twice-daily IMRT radiation treatments and 4 rounds of cisplatin+5 FU chemo were scheduled to start the day after Christmas. We were given 50/50 5 year survival odds with significant likelihood of impaired speech, taste, or swallowing. I got the feeding tube and chemo port in the same day and had about 3 weeks to pack on some weight and try to recruit and hire someone to run the work team.

The chemo and radiation were tough. The radiation oncologist opted to treat

lymph nodes on both sides of the neck, as well as the base of tongue. After about 6 weeks I was barely able to sip water and was relying on the feeding tube for most of my nutrition. Even with the tube, one of the hard parts of the treatment was the wasting - watching my weight drop and my pulse rise with each passing day of treatment. The hardest part for me was the depression. Thankfully, I had two excellent therapists, one of whom was my dear wife. I also found it helpful to join a healing service at church. A third very helpful resource was a survivor referral by SPOHNC.



The recovery period was in certain ways harder than the period in active treatment. Without the appointments filling the days, and with the kids at school and my wife at work, I was alone at home. At that time the U.S. had invaded Iraq so I could aptly fill my day with TV coverage of the invasion. My sense of taste was shot. When I tried to eat, every third bite seemed to wind up coming out my nose. I became very impatient with my recovery and my inability to meet milestones I had set that proved to be unrealistic.

Gradually by summer, I was able to return to work part-time, shutting the office door as I hung my bag filled with Ensure from the ceiling. Eventually, I was able to wean myself off the feeding tube on a diet of peanut butter, cream and instant breakfast. One big achievement was getting back to the swimming pool to show off my new "second belly button" from the banished feeding tube. Over many months my taste returned and I was able to start exercising. I was able to progress from yoga at a nearby senior center to completing my first half marathon, Olympic triathlon and then full marathon 18 months after treatment. Better yet, I was able to return to coaching the kids' soccer and basketball teams. The period of recovery was a remarkable uplifting experience of feeling better in every way with each passing day. In ways I felt like my quality of life and certainly my appreciation was improved

with the experience. At the same time I was deeply respectful of SPOHNC members who face down even greater challenges.

Fast Forward 17 Years

My wife and I are looking forward to our 35th anniversary this year. Our children have graduated college, left home, and started successful careers. The company was very successful, and I am transitioning into retirement. By almost all measures we have been blessed and ecstatic with my recovery. One radiation side effect that did not resolve was severe dry mouth. I eat slowly but without dietary limitations or any impairment of taste. We have come to cherish our long dinners. For the most part I am able to eat in restaurants and social events, although I sometimes struggle with swallowing and may need to take a break for an hour or more. I also have had \$50K+ of dental work, almost none of which was covered by insurance. (This is an issue I have contacted SPOHNC about in the past and would be happy to support or join an advocacy mission to try to get this injustice addressed.) *EDITORS NOTE: SPOHNC continues to work with The Center for Medicare Advocacy to address these issues.* Overall, we were grateful with being able to see these as surmountable obstacles, with cancer staying comfortably behind us in the rearview mirror.

Last spring, our younger daughter completed her masters degree in public health and was accepted into the Peace Corps. To celebrate graduation and enjoy some family time together prior to her 27 month mission in Botswana, we booked another 'trip of a lifetime.' This time we planned to hike the Inca Trail to Machu Picchu in Peru, and then on to an 8 day cruise on a small ship in the Galapagos Islands off Ecuador. We met the 4 day challenge of the trail and experienced Machu Picchu at sunrise, then headed on to meet our Galapagos cruise crew and mates feeling great and ready for the easy life at sea.

One of the attractive features of the itinerary that we chose was the amount of snorkeling, kayaking, and paddle boarding. We are all strong open water swimmers and certified scuba divers. On the first day we geared up in wet suits, along with masks,

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fins and snorkels. The rich marine life that the Galapagos is renowned for is due in part to cold Pacific currents in the area. About half way into the first snorkel outing, I noticed I was not feeling well – my breathing was off and I was feeling congested. We completed the dive but I was not well upon reboarding the ship. I had water in my lungs and a pounding headache. With only 14 passengers and a small crew on ship, the first aid resources were limited. It turns out that our Captain/guide Morris had a blood pressure (BP) cuff and took a reading. The number was absurd – 240/180. I had never had any prior issues with hypertension, I was not panicked or anxious about the dive or being on ship. I had 60 years of experience swimming in cold water in the Great Lakes. We rechecked the number. Both arms. All crazy numbers. Options at sea were limited so we agreed I would go down to our bunk and try resting for a bit before Captain Morris called on the radio for advice.

After a rest, the fluid seemed to be clearing from my lungs and I was breathing better. But my BP was still alarmingly high. At that point Morris called on the radio and we arranged for him to take me by dinghy to a small village on a nearby island with a medical clinic that could check me out. At the clinic, a doctor confirmed that my BP was dangerously high; she gave me some medicine, and tracked the BP until it reached a healthy level and seemed stable. We rode back and rejoined the ship for dinner. I decided to lay low the next day in hope that the BP surge was an isolated event, but unfortunately it wound up very high again. At that point the ship had moved away from the village where the clinic was, but the next island had a hospital. We pretty much repeated the previous day protocol in the hospital ER – took meds, the BP came down, and we returned to ship, only to revisit the hospital that same evening because my BP medications were not holding down my BP. I was given an additional medication to use and rejoined the ship. On day 3, it was wash, rinse, repeat – the BP was up over 200 again, and we were headed to a portion of the itinerary in which the only option was medivac

helicopter. Rather than risk that and continue to impose on everyone else’s trip of a lifetime, my wife and I opted to bail on the cruise and make our way back to Michigan.

On returning, my BP continued to be very high. Being Sunday, our only option for help was the ER. It turns out that BPs in the range I was experiencing are considered an ‘urgent hypertension event’, i.e. one that results in a flurry of tests and multi-day admission. The BP was controlled in the hospital by IV beta blocker and stayed pretty normal through a lot of bed rest. My lead MD was a nephrologist. He explained that the kidneys play a critical role in blood pressure regulation, as well as being highly vulnerable to damage from high blood pressure. After 4 days I was finally discharged with a tentative diagnosis of pseudopheochromocytoma, which online looked like a fancy billing code for a panic attack. I knew that was not right and not the end of the story.

I was discharged with prescriptions for both a beta blocker and ACE inhibitor to control BP. I wound up going back to work and being able to resume my exercise regimen and normal activities. My wife and I had planned a visit to her brother in Boulder Colorado and then I had work travel to two technical conferences in my field. In Colorado, we spent a couple of nights at ~10,000 ft elevation and I noticed I again was not feeling well and my BP was running very high. It was somewhat better after we came down to a lower elevation. Then, at my work conference, I was very high again – winding up in urgent care on one evening and then the ER on the following evening.

As I had been having recent changes in my swallowing and speaking, it occurred to me that there may be a connection of the BP to long term radiation effects. As I searched, I turned up references to baroreceptor failure. I learned there are several structures in the body that regulate blood pressure, and one of these that plays a strong role in renormalizing blood pressure after surges to stressors (e.g. ‘fight or flight’ response) is located along the carotid artery, which was in the field of radiation to my throat. The research also informed me that baroreceptor failure can be associated with unruly blood pressure on both the high and low end.

I felt like this was a significant finding. Being relatively uncommon, baroreceptor

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failure was outside the expertise of the team that had been treating me. In my mind, I was being treated as if I had a plumbing problem, when actually I have an electrical problem. Baroreflex failure is considered to be a dysfunction of the autonomic nervous system. This eventually led me to reach out to the Autonomic Dysfunction clinic at Vanderbilt. I also discussed BR failure with my local hypertension doctor and he felt this was plausible. We switched my medication to clonidine and off the beta blocker. I got a referral to Vanderbilt, but they were booked over three months out.

I began tracking blood pressure and trying to correlate it to stressors and modifying my behavior to avoid them. It turns out the stressor list is pretty long, and includes a number of stimuli that despite the label do not feel at all stressful. These include social interaction, exposure to cold, salty food, mental concentration, and sexual arousal in addition to more obvious stressors such as aggression, pain, and dealing with insurance claims or car dealers. The baroreflex failure also meant that my body was not able to regulate falling blood pressure either. Alcohol consumption and post-exercise vasodilation also could cause significant drops in blood pressure. The typical manifestation of this is sluggishness and orthostatic hypotension, or severe light headedness or fainting when standing up. For the most part I am able to manage this by doing a few squats to move any blood that has pooled in my legs. Compression socks are also effective.

Over 10 months after the ill-fated snorkel trip, we finally made it in to Vanderbilt in mid-April of this year. It was very reassuring that the team there seemed to be knowledgeable and experienced in treating patients like me. They made some adjustments in the medication protocol, but more importantly were able to convey that this problem could be managed with modest impact on quality of life or life expectancy. It was so relieving to know I was not necessarily in the fast lane to a stroke, heart attack, or kidney damage.

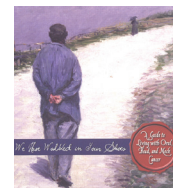
A few challenges do remain. Either the BP or the medication protocol has reduced my stamina. I have had to give up running but am still able to enjoy swimming and biking. Recent echocardiograms and blood work are showing possible impact on the heart and kidneys, but the exercise

limitations seem primarily attributable to a consequence of baroreflex failure being an inability of my heart rate to track with my blood pressure – as muscles demand more blood flow, healthy hearts increase volume through a combination of increased heart rate and increased blood pressure. With my heart rate lagging, my exertion level becomes uncomfortable and unsustainable.

At the time I am writing this, I am still hoping to manage this condition with a bit more stability. I would welcome hearing from other SPOHNC survivors or care providers with experience dealing with baroreceptor failure. I am particularly interested in experiences or guidance others have had which are relevant to controlling my BP surges while being socially, physically, and sexually active. And, while we do not feel like a trip to visit our daughter in Botswana is a good idea, I would welcome input to avoid giving up other adventure travel or volunteer activities without an ER doc accompanying me.

~ Mike Wixom - ultracap@aol.com

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Survivor News

SPOHNC's Executive Director & Outreach Administrator Meet "With Love, Me" Campaign Participants

Sharon Taylor, MD, Medical Oncologist and head and neck cancer survivor, and her husband, Willie Covington, recently joined SPOHNC, Merck and other cancer survivors and caregivers at SubCulture, in NYC for an event celebrating the Merck "With Love, Me" campaign. SPOHNC's superhero, Jim Kelly, was also in attendance, as well as Katie Couric, who moderated the event.



Doctor Taylor and many other survivors and caregivers were invited by Merck to participate in the campaign, writing letters to themselves, pre-cancer diagnosis. Some of the letters were shared by video and in live readings at the event. The evening was powerful, insightful, emotional (there were tissues on every seat in the theatre space) and an amazing tribute to the strength and fortitude of all cancer patients, survivors and caregivers. SPOHNC is grateful to be part of Merck's "With Love, Me" campaign.



It was our honor and pleasure to be able to finally meet Sharon and Willie. Sharon joined our SPOHNC family in February as a volunteer for our National Volunteer Survivor Network. She has since written her sharing story for our February 2019 issue of "News from SPOHNC," connected SPOHNC with a feature article author for the newsletter and is now Co-Facilitator for the SPOHNC Durham, NC Chapter support group. In her spare time, Sharon has begun "throwing" pottery – something she always wanted to do but never had the time.

It was wonderful to meet and spend time with Sharon and Willie. We are all so grateful that they were able to make the long journey from Raleigh/Durham, North Carolina, to join us for such an amazing evening.

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