

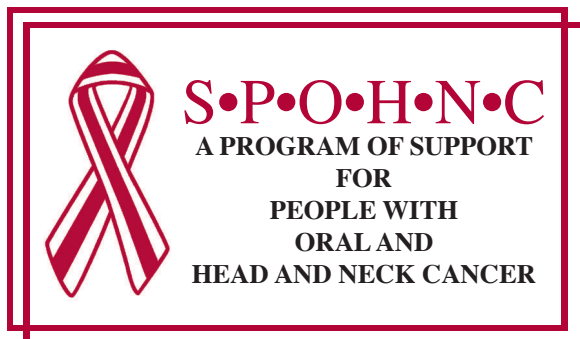
NEWS FROM S•P•O•H•N•C



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Standard of Care vs. Reduced Dose Chemoradiation After Induction Chemotherapy in HPV + Oropharyngeal Carcinoma Patients

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Epidemiology

Recent epidemiologic studies demonstrated a decline in the incidence of squamous cell cancers in the larynx, hypopharynx, and oral cavity, attributed to decline in tobacco use. At the same time the incidence of oropharyngeal squamous cell carcinoma (OPSCC), arising in the base of the tongue and the tonsillar region, caused by human papillomavirus (HPV) has significantly increased. HPV 16 is the most commonly isolated type, but other high risk (HR) serotypes, HPV 18, 31, 33 and 35, also showed an association in development of OPSCC. The incidence of HPV-associated OPSCC now accounts for over 70% of newly diagnosed OPSCC in the United States.



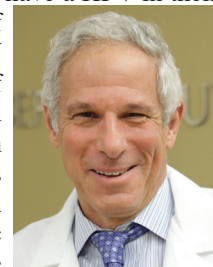
Risk Factors

The HPV virus is transmitted sexually via bodily fluids, and a high lifetime number of sexual partners is associated with an increased risk of OPSCC. Current studies suggest that oral-oral transmission (ie, kissing) is rare and most importantly that most partners effectively clear any active infections. Consequently exposure to HPV virus rarely leads to OPSCC and carcinogenesis does not occur immediately. Based on studies in cervical cancer it is known that most HPV infections, typically resolve within 6 to 12 months. The median timing of “pap smear” detected

precancerous cervical lesions in women occurs approximately 10 years after the median age of sexual debut. The European Prospective Investigation into Cancer and Nutrition cohort (EPIC) study identified 135 patients with OPSCC for which old blood samples were available. Anti HPV antibodies were present for some of them more than 10 years before diagnosis of OPSCC. Given that longest lag time reported in this study was only 13.7 years it is highly possible that true lead time from exposure till carcinogenesis may be much longer. Second it is unclear at what point from virus exposure the HPV antibodies are produced and are detectable, even though antibodies to HPV “Early Antigens” may be detected up to 10 years before cancer is detected however these tests remain experimental.

Diagnosis

Although HPV testing of the cervical area in women, “pap smear”, has been used for surveillance for cervical cancer, there is no clinical equivalent of “pap smear” or saliva test for OPSCC and should not be recommended outside of the research purposes. Additionally detecting HPV infection at a single time-point in saliva has little value in assessing the risk of cancer development. As much as 3% of the adult population will have a HPV in their saliva at any given time – far in excess of the risk for cancer, and the absence of HPV detection does not rule out the possibility of past infection. There are no FDA-approved saliva or blood tests to detect HPV infection and there are no prophylactic strategies available in OPSCC even for patients with multiple sexual partners since prophylactic tonsillectomy does not address the entire anatomic area at risk; patients still have a risk of cancer in the base of the tongue. OPSCC is identified because of local symptoms including an isolated neck mass in an adult. Patients should be evaluated by examination, scans and biopsy. Often the primary tumor in the tongue or tonsil may be too small to be symptomatic or obvious on examination. Tumors may wax and wane in size with antibiotics giving a false sense of safety.



Treatment of OPSCC is very complex and if possible should be done at institutions with extensive experience in treatment of cancers of the head and neck, not only to get the most cutting edge therapy, but also to ensure appropriate diagnosis. Significant differences in HPV positivity testing used in clinical practice highlights a concern for accuracy when p16 is used as a stand alone HPV test. In our opinion the combination of p16 with a HPV DNA testing by polymerase chain reaction (PCR) or RNA Scope are well-accepted standards that offer high sensitivity and specificity for identifying HR HPV in tumors.

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Prognosis

HPV positive oropharyngeal cancers have excellent prognoses. Locally advanced stage cancers are cured in 65-95% of cases. HPV OPSCC is highly responsive to therapy. Due to the significant difference in prognosis between HPV positive patients compared with patients with similar stage HPV negative tumors seen in multiple prospective trials published over the past decade, separate staging systems have been established for HPV positive and HPV negative oropharyngeal carcinomas. In addition, HPV positive and negative patients can frequently be misclassified due to imperfections of tests used for HPV detection. Hence center expertise and experience will impact on prognosis. It is also worth mentioning that even though age, HPV subtype and smoking seem to be relevant in patient’s prognosis they are not considered in the eighth edition American Joint Commission on Cancer (AJCC) clinical or pathological staging, highlighting the need of real expertise in OPSCC when making treatment recommendation. Based on large studies it is well known that the risk of death in HPV positive OPSCC increases significantly with each additional pack-year of smoking. Based on some studies patients HPV positive OPSCC with >10 pack-year smoking history should be classified as high risk, although we use 20 pack years, since this group of patients



also has an otherwise excellent prognosis which is partially compromised by tobacco exposure. Although data is sparse, it is also possible that HPV types other than HPV 16 may have a worse prognosis than HPV 16 positive cases.

Side Effects of Current Standard Treatment Options

Current standard of care for OPSCC is recommended for HPV positive OPSCC despite significant differences in prognosis between HPV positive and HPV negative patients and requires high dose of radiation, combined often with high dose chemotherapy. Current therapies for HPV positive OPSCC may be more intensive than necessary to achieve cure, leading to frequently occurring acute toxicities like dermatitis, mucositis, and chronic late side effects such as dryness of the mouth, difficulty swallowing, feeding tube dependence, hypothyroidism and speech-related toxicity. Multiple clinical trials aiming to reduce dose of radiation and/or chemotherapy have been opened in order to reduce early and late treatment-related morbidity and improved early and late functional outcomes while maintaining excellent cure rates. Participation in these trials should be strongly encouraged. Patients with HPV-positive OPSCC tend to be younger with fewer comorbidities compared with those with HPV-negative disease; they will survive and may carry progressive radiation complications for decades.

Promising Results of Treatment “De-Intensification”

Promising results were reported by Eastern Cooperative Oncology Group-American College of Radiology Imaging Network (ECOG-ACRIN) with 51 patients treated with induction chemotherapy followed by low dose of radiation with chemotherapy, using 54 Gy instead of standard 70Gy. There was no difference in cancer progression at 2 years between low and high dose of radiation. Since

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all treatment failures occurred in patients with a >10 pack-year smoking history, within the first 20 months of registration a careful patients' selection should be taken into account in other clinical trial designs to ensure appropriate treatment recommendations. Patients that responded to induction chemotherapy who received reduced-dose radiation also appeared to have significantly less late swallowing dysfunction. The small sample size is a limitation to interpretation of these outcomes and the subset analyses therefore larger studies are required before these promising results can be applied in clinical practice.

Cutting Edge Treatment Strategies

There are several de-intensification strategies tested in clinical trials:

1. Replacement of chemotherapy with potentially less toxic targeted therapy but no dose reduction (NCT01302834).
2. Omission of chemotherapy, using radiation alone (NCT01302834).
3. Dose reduction, chemotherapy and radiation (NCT01302834).
4. Chemoselection, the use of induction chemotherapy to identify patients with disease sensitive to therapy and only responders receiving dose reduced therapy (NCT01706939).
5. Induction chemotherapy to increase local and regional control with reduced radiotherapy, improve functional outcome, and reduce metastases in locally advanced disease.
6. Surgical patients stratification into low, intermediate and high risk based on strict post resection, pathological criteria and dose reduction strategies customized based on risk category.

The Quarterback 1 Trial (NCT01706939) that was offered at our institution recruited participants to explore using induction chemotherapy in patients with stage III-IV non-metastatic HPV-associated OPSCC, with ≤ 20 pack-year smoking history to treat for distant disease risk, improve functional outcomes and increase local control with less radiotherapy. Patients were randomized 2:1 to low versus standard dose chemoradiotherapy.

Patients received three cycles of docetaxel, cisplatin, and 5-FU induction

therapy. Those with a radiographic response were randomized to reduced- (56 Gy) or standard- (70 Gy) dose radiotherapy with weekly carboplatin and cetuximab or carboplatin only. HPV positive OPSCC patients who received reduced chemotherapy and radiation (CRT) had similar cancer 2 year progression rate compared to those receiving standard CRT (83.3 vs. 87.5%). These results support more robust study of the potential clinical benefit of induction therapy and radiation dose reduction as a treatment option in locally advanced HPV+ OPSCC in non-smokers. Interestingly all 3 treatment failures were local or regional and 2 of 3 occurred in non HPV16 HR variants (HPV 18 and HPV 33). Promising results encouraged us to extend this trial to the Quarterback 2 that is open and actively enrolling patients. In The Quarterback 2 trial, no randomization is done, and all patients receive low dose of CRT and are followed for cancer progression and survival after treatment completion.

Significant improvements were made in surgical resection, a modality often applied in the management of OPSCC. Transoral robotic surgery (TORS) and utilizing miniaturized instruments to perform resection of OPSCC through the open mouth, offer clear advantages over a mandibulotomy which was required to gain sufficient access to the oropharynx for resection, resulting in functional and cosmetic impairments. Transoral laser microsurgery (TLM) is another emerging technique for the management of laryngeal and other head and neck malignancies replacing traditional surgery.

When coupled with digital magnification, it allows for accurate dissection without the morbidity and functional deficits of open surgery. The Sinai Robotic Surgery (SIRS) clinical trial offered at our institution (NCT02072148) was designed to explore the combination of TORS and risk-based, de-intensified adjuvant radiotherapy or chemoradiotherapy or just observation in patients with HPV-associated OPSCC.

Patients deemed low-risk after resection are observed, intermediate-risk patients receive adjuvant low dose radiotherapy alone, and high-risk patients are treated with low dose radiation and weekly cisplatin. Results of this trial will determine if

the combination of minimally invasive surgical techniques with reduced intensity adjuvant therapy proves to be less toxic than current standard of care management and equally if not more efficacious. ECOG has also completed a trial of surgery based e-intensification which will be analyzed in the next 2-3 years.

Immunotherapy

Traditional chemotherapy is currently used in the curative treatment of HPV positive OPSCC and is entirely different from immunotherapy that has recently stormed into our offices as another treatment option when treating recurrent cancer of the head and neck. Immunotherapy is based upon the biologic notion that the patient's own immune system may eradicate or slow down the growth of malignancy. Knowing that tumors evolve ways to hide from our own immune system, the main goals of immunotherapy are first, to help in the recognition of cancer as foreign by the immune system and second, to stimulate a robust immune response. HPV positive and negative OPSCC fights back normal immunologic clearance, in part, through the development of immunologic tolerance that is mediated by expression of ligands for immunologic checkpoints such as PDL1 on tumor tissue within the tumor microenvironment blocking our own immune system from accessing the tumor.

As of now there is no evidence of greater immunotherapy efficacy in HPV positive as opposed to HPV negative tumors. New HPV directed therapeutic vaccines are being investigated in early trials for treatment of recurrent or metastatic HPV cancers.

Conclusion

Careful patient selection for treatment of HPV positive OPSCC is critical in order to avoid jeopardizing the excellent outcomes that are achieved with the current standard of care therapy in this patient population; therefore de-intensification should not and is presently not recommended outside of a clinical trial. Immunotherapy seems to be a very interesting therapeutic option for patients with HPV positive tumor but more data is needed to make any treatment recommendations.

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Editors Note: Krzysztof Misiukiewicz is an Assistant Professor of Medicine at the Tisch Cancer Institute. His clinical expertise is in medical management of head and neck and thyroid cancer. He is a principal investigator on numerous clinical trials for head and neck cancer and thyroid patients available at Mount Sinai Hospital.

Dr. Marshall Posner is a Professor of Medicine and Director of the Human Monoclonal Antibody Laboratory in the Department of Cell and Gene Therapy at Mount Sinai School of Medicine. He is also Medical Director of the Head and Neck Oncology Center at the Mount Sinai Medical Center, and Medical Director of the Clinical Trials Office for the Tisch Cancer Institute in New York City, New York. Dr. Posner received his MD from Tufts University School of Medicine (1975), and completed his internship and residency in internal medicine at Boston City

Hospital (1978) and a fellowship in medical oncology at the Dana-Farber Cancer Institute (1981). Dr. Posner has been an advocate for clinical research and multi-disciplinary care in head and neck cancer. He has and continues to participate in international symposia and on planning committees devoted to advancing clinical care and directing clinical research in head and neck cancer.

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Immunology at Icahn School of Medicine at Mount Sinai. He completed residency training in otolaryngology-head and neck surgery at Washington University, Barnes Hospital. Dr. Genden then completed fellowship training in head and neck oncology and microvascular surgery at The Mount Sinai Medical Center and a Masters in Healthcare Administration at Harvard University.

Dr. Genden's expertise in management of oral cancer and reconstruction of the head and neck has contributed to the national reputation for excellence at Mount Sinai Hospital. Dr. Genden's basic science laboratory focuses on transplantation immune biology of the trachea and larynx and is funded by The National Institute of Health. He has published nearly two-hundred manuscripts and chapters and is the author and editor of five books.

A TIME FOR SHARING...My Path Forward

It was June of 2016, and I hadn't uttered a word in three months. I wasn't on an extended silent meditation retreat, nor had I taken a spiritual vow of silence. This was a forced muzzle. My speech pathologist, whom I adore, urged patience. It was running razor thin. Three months prior, I had undergone a laryngectomy, a surgery to remove my larynx. The procedure left me without a voice box, and with a hole in my neck through which I'll breathe until I cease to do so, hopefully a long time from now. During the operation, surgeons implanted a voice prosthesis, but thus far my attempts at speech were futile.

My cancer journey started in 1997 when malignant lymph nodes were found in the right side of my neck. I was 41 years old, married, with children in elementary school, and had just started a boutique documentary production company. I had many reasons to live. But driving home after being diagnosed, the fear that I wouldn't be around to see my children graduate from middle school enveloped me.

After undergoing a radical neck dissection, a PET scan located the primary tumor – a squamous cell cancer in my tonsil. My radiation oncologist recommended aggressive radiation treatments, a hefty dose over a wide field, and was confident about my chance for survival. The radiation regimen was awful in every sense. I had burns outside my neck and inside my

throat. I couldn't keep down even the small amounts of food I was able to swallow. Over the course of seven weeks of radiation treatments and the months that followed, I lost fifty pounds. Cancer treatments had overwhelmed my body and spirit.

At my wife Frances' urging, we ventured to the Cancer Support Community (formerly the Wellness Community) to attend support groups for newly diagnosed cancer patients and their caregivers. I felt afraid and depressed, but I didn't think I needed help. As with most things in my life, my wife knows best. After only a few weeks of group I still felt fearful, but no longer alone. Every person in the room with me



was experiencing the same thing. At times we cried, knowing there's healing power in shedding tears, then a few moments later we made jokes, knowing that laughter is indeed the best medicine. We mourned our physical and emotional losses, then celebrated the insights we had gained precisely because of those same losses. Sometimes we cursed our doctors for seeming to lack empathy, then we praised them for the times they stepped up and became our rock stars. Most of all, I learned from other people's experiences.

Down the hall in another room, my wife was meeting with fellow caregivers. They shared experiences and emotions unique to the caregiver. I'm sure they

sometimes cursed us. Being a cancer patient isn't easy. Being a caregiver, in some ways, is harder.

It would be hyperbolic to say that sitting in a room and talking with cancer patients saved my life. However, it wouldn't stretch the truth to say it helped me live more fearlessly. I was motivated by group members who, despite being exhausted by cancer treatments, still found tranquility and energy in meditation, exercise, music, yoga and other mindfulness methods.

I was also inspired by those who found ways to fully experience life even while tackling a terminal diagnosis. Witnessing the grace these people exhibited led to the development of one of my pet peeves - obituaries that start with a sentence something like this: "After 3 years, Jane Smith lost her battle with cancer..." In my opinion, that sentence incorrectly defines victory and defeat. Eventually, we're all going to die. The cause could be cancer, or it could be a variety of other illnesses, injuries, or accidents. Usually, we don't define death as defeat in those cases. Don't get me wrong, fighting cancer is a battle. But I firmly believe victory should be measured not by how long we live, but by how well we live. The real battle is between despair and hope. It's between stress and mindfulness, between isolation and community. Winning these battles can help us to live longer. These lessons have carried me through life, although I've needed occasional refresher courses.

With a robust dose of radiation in my rearview mirror, and with lessons

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learned in our support groups, Frances and I returned to the normal, often hectic responsibilities of parenting and careers. Weekly support groups were replaced with kids' school activities and seemingly year-round youth basketball and soccer games and tournaments, sometimes in far off places.

My work took on new meaning. I restarted my company and developed documentary projects that would feed my soul, not just my wallet. I don't want to come across as solely high-minded. I've produced my share of inconsequential and shallow fare. But I have been able to strike a balance by making films about deeply relevant subjects, like social issues, and civil and human rights. In doing so, I have been fortunate to win a few accolades, see the world, and meet intensely interesting and historically significant individuals.

I had returned to my old self, but cancer's shadow followed me. I wasn't overly concerned with a recurrence of the disease, but after about five years I started to feel aches, pains and growing tightness in my neck. I've heard radiation described as "the gift that keeps on giving." More like a scourge than a gift, the long term adverse effects of radiation cause injury. Fortunately, the art of radiation treatment has advanced. Today, tumors are more finely targeted, lessening collateral damage to anatomy that surrounds cancer cells.

Twenty years ago, radiation fields were not as precise. I endured aggressive radiation treatments to the front and both sides of my neck. Very quickly, the radiation killed most of my salivary glands. Most of the other radiation injuries came on gradually. Over the years, I had many surgeries to remove polyps from my vocal cords, and to expand my narrowing esophagus. Tissue in my neck began to scar.

Once again, my wife recommended we attend a support group to better cope with the issues presented by long term radiation. We found ourselves at a head and neck cancer support group at Keck Medicine of USC started by my speech pathologist, Brenda Villegas, my otolaryngologist and surgeon, Dr. Uttam Sinha and a few cancer survivors. I was fifteen years removed from my original group experience but instantly felt welcome, and benefited from members' collective empathy and suggestions about methods to

reduce aches and pains.

The interventions of my medical team slowed but could not halt my radiation-induced fibrosis. By early 2015, my trachea had constricted so much I was constantly short of breath. As my breathing difficulties increased, Dr. Sinha advised me that a laryngectomy was likely in my future. He promised my quality of life would vastly improve in the long term. His immediate concern was that I might have a respiratory crisis at home or work, requiring paramedics to perform an emergency tracheostomy in the field, a procedure that usually yields less than stellar results. He urged me to consent to a laryngectomy.

A laryngectomy is a surgical procedure to remove all or part of the larynx. In simple terms the surgery involves the removal of the voice box. The trachea, or windpipe, is brought forward to the skin and attached to an opening (stoma) in the front of the neck. With the windpipe no longer connected to the mouth or nose, a laryngectomee (a person who's had a laryngectomy) breathes through the stoma. To restore speech, surgeons can opt to place a valve (voice prosthesis) that connects the back wall of the trachea with the front wall of the esophagus. Speech is formed by breathing in through the stoma; the voice prosthesis then redirects airflow into the esophagus, and then up and out of the mouth. When the procedure was described to me by my doctor and speech pathologist, my first emotions were apprehension and dread, followed again by denial.

Experience had taught me that a safe place to express fear and ask questions was a support group. My speech therapist recommended the group Nu Voices, also at Keck Medicine of USC. More than half of the group members had laryngectomies, the rest were caregivers. Some were able to speak with more clarity and resonance than others. Seeing and listening to them was like staring into a crystal ball. The experience was disconcerting and at the same time reassuring. I was impressed by the happiness quotient of group members. These people liked to joke and laugh. They appeared active. Although somewhat encouraged about what life may hold after a laryngectomy, I continued to stall. But soon my deteriorating condition was obvious to just about everyone. My work colleagues noticed my weakened voice from scarred

vocal cords. My wife said she could hear my labored breathing from other rooms of the house. Mild exertion left me severely winded.

On Thursday March 10, 2016, I went to a regularly scheduled doctor appointment. When Dr. Sinha heard me struggle to breathe and speak, he interrupted me and said, "We can't wait any longer, we have to do the laryngectomy now." Stunned but not surprised, I could no longer keep alive my denial. I couldn't invent any more excuses. As I sat in the exam room with my wife, Dr. Sinha attempted to schedule the surgery for the very next day. The operating room was booked solid. But he considered my condition so serious he didn't dare delay. He assembled a full surgical team to come into the O.R. on Saturday.

On March 12, 2016, I ceased to breathe through my nose and mouth, and I lost my voice box.

In the hospital, I communicated with hand-written flash cards with what we assumed would be my most common requests such as: "I'm cold." "I'm hot." "Suction." "Pain." I frequently used the "pain" flash card. A laryngectomy is a major surgery. During the recovery period, there is ample swelling and copious amounts of mucus and blood. And then there's the pain and care of the stoma, in effect an open wound about the size of a dime, now sutured to the trachea. In order to keep the stoma from closing, a tube must be kept inside it for weeks after surgery. It's exceedingly uncomfortable.

Before my surgery, Brenda, my speech pathologist, told me it would take three weeks to several months before I'd be able to speak. About a month after the procedure I made my first attempts at speech through my voice prosthesis. Nothing. I had weekly appointments with Brenda in which she coached me on proper breathing techniques to facilitate speech. Weeks passed. Aside from a couple of vowel sounds, I wasn't capable of saying a single word. Brenda assured me nothing was wrong and that previously radiated tissue takes longer to heal. When the swelling went down, she promised, I would talk.

Now it was June of 2016, three months after my surgery. I went into the bathroom,

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stared into the mirror and tried to count to ten. When “1” emerged from my mouth, I was taken aback. I pressed on, “2, 3, 4...” and all the way to 10. I hated the sound of my new artificial voice but I was relieved, happy to be able to communicate. Reactions to my voice vary. My 18-month old niece often cries when she hears it. My 5-year old nephew is fascinated by it.

Frances and I are now regular attendees at the monthly meetings of the Nu Voices laryngectomy support group. I’ve learned a lot about the daily challenges a laryngectomee must face.

After a laryngectomy, a patient’s path to recovery is riddled with obstacles, both physical and psychological. The surgery drastically alters some of the most basic human functions – speaking, breathing, and eating. As patients struggle to adjust to their new appearance and the severe change in the way they speak, they often withdraw and avoid social interaction. At some point, most wrestle with depression, isolation, loneliness, and fear. I did. In social situations, they can suffer from a lack of confidence. I sometimes still do. Imagine walking into a crowded restaurant, bar, or room, and being rendered effectively mute by loud crowd noise. There are no volume controls on a voice prosthesis and persons who speak with one are unable to loudly project their voices. Don’t expect a person with a laryngectomy to have a lively

conversation over a meal. Eating often blocks the flow of air through the esophagus needed to speak.

A laryngectomee’s quality of life will largely be determined by his or her ability to cope with the tasks of day-to-day living, and the overall psychosocial aspects of living with a laryngectomy. As a filmmaker and a laryngectomee, I decided I want to tell a story that will address these issues, and inspire folks who’ve had a laryngectomy or are facing one. *Segue* is a documentary about the transition from life with a voice box, to one without. It’s told through the experiences of the members of a choir in London, made up of individuals who have had laryngectomies. This music group is an initiative of Shout at Cancer, a charity that uses singing and acting techniques to help improve voice prosthesis speech. At its heart, *Segue* is a stirring testimony about the human capacity for resilience, even in the face of overwhelming adversity. I expect to start production by the beginning of 2018. If you’d like to get information or updates on the production, please email segueinfo@bbprods.com.

Today, I’m blessed with a quality of life more resonant than before my laryngectomy, just as my doctor promised. I take walks about six days a week, totaling 90-100 miles a month. I eat well. I still get stressed but I’ve learned how to handle it more effectively. In the past few years, I’ve proudly witnessed

my son and daughter graduate from the University of Southern California. I’ve walked my daughter down the aisle. And next year, I’ll be a grandparent. Twenty years ago, as I drove home from being told I have cancer, these are all experiences from which I thought I’d be absent.

I no longer hate my mechanical sounding voice. I view my disabilities arising from cancer and cancer treatments as battle scars, visible and audible signs of where I came from and what I was able to overcome. But I’m acutely aware I wouldn’t have reached secure emotional health without the love, support and encouragement of family, friends, my medical team, and the cancer survivors I am honored to know through support groups.

There’s a line in the Leonard Cohen song *Anthem* that speaks to finding one’s way out of whatever darkness envelopes you, and aptly describes my experience in support groups. “There is a crack in everything. That’s how the light gets through.” When I was at my emotional lowest, group members helped guide me to that sliver of light. In turn, the light helped illuminate my path forward. I’m forever grateful for that gift, and to the people who gave it to me.

~ Bill Brummell
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SPOHNC is very grateful for all that our Chapter Facilitators do each and every day to help those whose spirits need lifting, and who look to those who have “walked in their shoes” for encouragement, inspiration and advice. One such special person is our own Amy Beilman, Caregiver and Co-Facilitator of the SPOHNC Palm Coast Northeast, FL Chapter. We found out that Amy celebrated a birthday on September 10th!

Amy...your SPOHNC family wishes you all that you hope for this year, and beyond. For all that you give to others, we

are grateful. For all that you bring to your SPOHNC Chapter, we are blessed. We are in awe of your spirit, strength, knowledge and dedication. Thank you, and a very

**Happy Belated Birthday
to You, Amy!**



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CELEBRATING THE LIFE OF CAPTAIN DAN

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It is with deep sorrow that SPOHNC shares the news of the passing of a great man... Dan Stack, Facilitator of the Dallas/Baylor Irving, TX SPOHNC Chapter. The news came as a shock to all of those who knew and loved Dan – especially those who looked to him as their leader and their beacon of hope. One

such survivor is Dave Noble, who attended Dan's group for many years. Dave shared these words with SPOHNC.

"I was referred to the Irving, TX SPOHNC Chapter in 2005 after having tongue surgery, radiation and chemo. We had a great group with Dan Stack, our leader, who I nicknamed "Captain Dan." He was a Vietnam Navy man and we had a few military guys in our group. I sat next to Dan at the meetings and he would welcome us with coffee and things that were brought in. He would go around the table and ask everyone to introduce themselves and say what type of treatment we had and introduce the new members. He would ask if anyone had any issues and we would talk about them. Just before Christmas about 8 years ago, I brought in some music boxes and Dan said "What's in the bag Nobes?" It was a Frosty the Snowman music box. I took one out, remarking that it reminded me of many of us who are disfigured in the face but still keep "beating the drum." Sometimes when I was on the phone with him, if I was feeling down he would say "hold on Nobes" and play the music box for me. It always lifted me up and made me laugh. Captain Dan had a Big Heart and he and the group kept us laughing a lot - which we needed! I miss him so much." Former SPOHNC Indy North, IN Chapter Facilitator John Groves also remembered Dan... "I had actually met Dan at the SPOHNC 15th year celebration in New York. He was a wonderful person and will be sorely missed by all."

Dan came to our SPOHNC family following his diagnosis in 1998, when he attended the SPOHNC Atlanta, GA Chapter support group meeting. There, he found camaraderie and a sense of belonging, with other who were walking a similar journey.

After a job change and a move to Dallas in 2000, Dan saw a need, and began the SPOHNC Dallas Baylor Chapter, where he quickly became a strong leader, advocate and a source of inspiration for those who he welcomed into his group.

Dan was also a beloved volunteer for SPOHNC's National Survivor Volunteer Network, where he offered one to one support for those seeking someone to talk to about their concerns, worries and what they were going through. Nothing can compare to connecting with someone who has been down the road and travelled the same journey. Dan was there for many.

On Tuesday, October 10th, following the regularly scheduled SPOHNC chapter support group meeting, members of the Dallas, TX SPOHNC family, along with fellow facilitators Jack Mitchell and his lovely wife Maryellen, Chaplain Alan Wright and SPOHNC Executive Director, Mary Ann Caputo, all gathered together to pay tribute to Dan. The service was held in the chapel at Sammons Cancer Center.

Facilitator Jack Mitchell, survivor, fellow facilitator and longtime friend of Dan's, shared these words with those who had come to celebrate his life...

"It is hard to believe that Dan has left us for a better place. He was a very caring and beautiful person. I first came into contact with Dan in early 2002 when I found the SPOHNC Chapter in Irving, Texas. Like many and most OHNC survivors, I could not understand why I was not back to normal from my cancer journey, completed in October 2001. After searching the web, I found SPOHNC and from that, the chapter in Irving.

At the first meeting, Dan made me feel special and the group listened as I described all of the 'problems' I was experiencing. They all smiled, nodded their heads and commented, in unison..."Welcome to the New Normal."

Since that time, Dan helped us form three more chapters in the DFW area and has always been there for special events and was our 'rock' at the Irving meetings. Dan always had a way to make new survivors feel special and took away much of the anxiety of their recovery. He will be missed. Rest in Peace, my friend. I know there is a special place for Dan in Heaven. I am sure he will start a SPOHNC Chapter there."

Chaplain Alan Wright, Co-Facilitator of the Dallas group at Cvetko, and a good friend of Dan's, shared heartfelt words with those seeking comfort in the room. The Dallas area groups are blessed to have Chaplain Wright as a member of their SPOHNC family. He said: "I have a sign over the door in my office that reads, "Action Cures Fear" because my job can be kind of scary sometimes. The quote reminds me that I need to look past my fears and do what I've been called to do. So when I'm thinking to myself that I sure do have a lot of paperwork to do and it sure would be nice to sit here in this office all day, I remember how important it is to get up and go out on the floors and visit cancer patients. Once I'm out on the floors helping people I remember that action does cure fear.

Dan knew this as well. An oral cancer diagnosis can be a scary thing. When Dan was diagnosed, I'm sure he was scared but then he acted on his fear. He found out as much as he could about the cancer, he attended a SPOHNC conference, and then he began figuring out a way to help others with similar cancers. I never asked Dan about his faith, so I can't comment on it. Dan didn't seem to me to care much for sentimentality. He understood something that few people ever get—that love without action is just sentimentality. Dan knew in his heart of hearts that sentimentality never helped anyone.

He began the first SPOHNC support group in this area which spawned more SPOHNC groups in the area. He served as a resource for people. He would hear their fears, educate them, and celebrate with them. Dan loved others by helping others. May we



continued on page 8

Visit the SPOHNC website at www.spoync.org

continued from page 7

all honor Dan, by living a life where our love is accompanied by action.”

Mary Ann Caputo, SPOHNC Executive Director, spoke with deep emotion about the man who had made such a difference in the lives of so many, because he “understood the challenges of the disease and knew the importance of connecting with those who have “walked in your shoes.” Mary Ann shared the following... “throughout our lives, we are given the opportunity to meet very special and good people – Dan Stack was one of them. He will be missed by many, but especially by the SPOHNC family, who was blessed to have him as a part of our lives.”

The loss of someone so special will affect each of us in our own way, yet we must continue to support one another, as Dan supported so many along his journey. He will remain forever in our hearts and will be remembered as a man who had a genuine passion to help others, and provided encouragement and guidance, along with some laughs along the way. We will miss our dear friend and SPOHNC family member, Dan...

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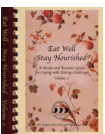
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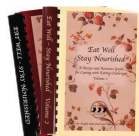
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Cozy Autumn Recipes from Eat Well Stay Nourished A Recipe and Resource Guide For Coping With Eating Challenges

*Compiled and Edited by Nancy E. Leupold, Survivor, Founder & President Emeritus
If you have difficulty with chewing and swallowing, try these recipes from Volume Two.*

Wild Rice, Chicken and Ham Chowder

2 parsnips, peeled and chopped coarse
1 baking potato, scrubbed and chopped coarse
1 onion, chopped
2 cloves garlic, chopped
2 small jalapenos, cored, seeded chopped (can be omitted)
4 c. chicken stock
3 tbsp. butter
½ c. diced celery
¾ c. diced bell peppers
¾ c. diced sweet potato
¾ c. corn kernels
½ c. milk
2 c. cooked wild rice
1 c. cooked, diced chicken
½ c. smoked ham, cubed
Worcestershire sauce to taste
Salt and pepper



Put first 6 ingredients in large saucepan. Bring to a boil, reduce heat and simmer until vegetables are extremely soft – about 30 minutes. Cool slightly and then puree in a blender or food processor until smooth. When soup base is cooking, heat butter in large frying pan. Add celery, peppers, sweet potatoes and corn and sauté over medium high heat until soft and slightly browned. Add salt and pepper. Put soup base in clean saucepan. Add milk and bring to simmer. Add rice, chicken, ham and vegetables. Add splash of Worcestershire sauce. Add more salt and pepper if needed. Simmer a few minutes to blend all flavors. Serves 9. 226 calories/serving.

~ Nancy J., MN

Pumpkin Crème Mousse

1 c. canned pumpkin
2 pkg. instant vanilla pudding (sugar free)
1 tsp. pumpkin pie spice
1 c. fat free cool whip
1 c. milk



Mix all ingredients together for one minute at low speed with hand mixer. Refrigerate for several hours until firm. Serves 6. 100 calories/serving.

~ Mary R., IN



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IMPORTANT Medicare News Update *from The Center for Medicare Advocacy*

Community Statement on Medicare Coverage for Medically Necessary Oral and Dental Health Therapies

SPOHNC, along with nearly 100 additional non-profit health and human services organizations in the categories of National Associations of Medical Specialists, National Voluntary Health Organizations, Health/Aging/Medicare Advocacy Organizations and Dental Organizations is proud to join in support of Medicare coverage for medically-necessary oral/dental health therapies.

It is well established that chronic diseases disproportionately impact Medicare beneficiaries and impose a substantial cost on the federal government. It is also well established that untreated oral microbial infections are closely linked to a wide range of costly chronic conditions, including diabetes, heart disease, dementia, and stroke. In addition, oral diseases have been documented by researchers and medical specialty societies as precluding, delaying, and even jeopardizing medical treatments such as organ and stem cell transplantation, heart valve repair or replacement, cancer chemotherapies, placement of orthopedic prostheses, and management of autoimmune diseases.

Despite these factors, most Medicare beneficiaries do not currently receive oral/dental care even when medically necessary for the treatment of Medicare-covered diseases. In fact, Medicare coverage extends to the treatment of all microbial infections except for those relating to the teeth and periodontium. There is simply no medical justification for this exclusion, especially in light of the broad agreement among medical specialists that such care is integral to the medical management of numerous diseases and medical conditions. Moreover, the lack of medically necessary oral/dental care heightens the risk of costly medical complications, increasing the financial burden on Medicare, beneficiaries, and taxpayers.

At least six major insurance carriers offering dental plans provide enhanced periodontal and preventive coverage to targeted enrollees with conditions such as diabetes, heart disease, stroke, head/neck cancers, and transplants. According

to some reports, such coverage has realized important benefits, including markedly lower hospitalization and emergency department admission rates as well as substantial cost reductions. On a further note, veterans getting care through the Veterans Health Administration receive medically adjunctive oral/dental treatment in many instances when a dental diagnosis affects their medical prognosis. These are all important steps forward, and medically necessary oral/dental healthcare including periodontal treatment should be provided in traditional Medicare as well.

The Medicare program and all its beneficiaries should not be without the vital clinical and fiscal benefits of coverage for medically necessary oral/dental health therapies. Given the significant potential to improve health outcomes and reduce program costs, we urge Congress and the Administration to explore options, including utilization of existing authority, for extending such evidence-based coverage for all Medicare beneficiaries.

CHAPTER NEWS

Hershey, PA SPOHNC Chapter Holds a Garden Party!



For those who think that people who are going through or have gone through head and neck cancer are somber, no-fun folks: Members of the Penn State Hershey SPOHNC Chapter, their families and friends, attended our annual Summer Garden Party at the home of Steve and Karen Rhoad on Wednesday evening, August 30. Karen is a member of our group (and a wonderful hostess!), and this was the third (maybe fourth!) time that she and Steve graciously hosted the party.

And what a great evening it was for a party! Friends gathered together on a

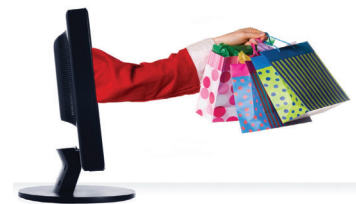
beautiful summer evening, good food, and interesting conversation. (Even some good jokes!) A great big thank you to Karen and Steve for hosting once again. And kudos to their very tall son, Spencer, for taking this fantastic picture!

~ Patrice Saurman



***We've heard of Garden Parties,
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A Toast To a Special Lady *Sandra Lynn "Sandy" Bates*

SPOHNC was deeply saddened to learn of the passing of a dear and very special member of our SPOHNC family - Sandra "Sandy" Lynn Bates. Sandy passed away on Thursday, March 2, 2017 in Phoenix, Arizona.

She was born on September 28, 1960 in Pittsburgh, Pennsylvania. She attended college at Arizona State University receiving her Bachelors of Science in Nursing. Sandy was a pediatric nurse, who worked in the NICU



at Phoenix Children's Hospital, then moved on to many other nursing opportunities. She worked for Blue Cross Blue Shield of Arizona in Medical Grievances and Appeals until retiring very recently on February 1, 2017.

Sandy was the dedicated facilitator of the SPOHNC Phoenix, AZ Chapter support

group for 15 years. As a nurse and a survivor, Sandy had unique professional and personal knowledge to bring to the newly diagnosed patients, survivors and family members who attended her support group meetings each month. Sandy was also a volunteer for SPOHNC's National Survivor Volunteer Network match program, since 2004. She attended SPOHNC's 20th Anniversary and Celebration of Life in 2011, where we had the privilege of meeting her and spending time together.

Sandy had an amazing spirit and a zest for life – her favorites were her children, her friends and a nice glass of wine. Sandy also enjoyed traveling locally and internationally. Watching a sunset on the beach gave her the most joy.

Sandy is survived by her loving spouse, Jody; two sons, Gregory and Zachary Griffin; children by marriage, Kelcey and Kaleigh Bates, and Kyle and Matt Ferguson; a brother, Steve Stein; beloved (favorite) ex-husband, Pat Griffin; and many other loving family and friends.

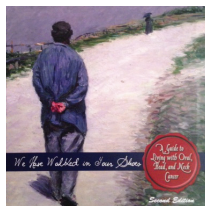
Sandy's ex-husband, Pat Griffin, recently contacted SPOHNC to tell us about a unique and special way that Phoenix chose to pay tribute to Sandy. On October 15th, CC's Mesquite Broiler in Phoenix, held a fundraising event in Sandy's honor. Part of the proceeds of the event were contributed to SPOHNC. Pat, organizer of the event, served as a guest bartender. The event raised several



hundred dollars for SPOHNC. According to Pat, a good time was had by all, and there was a toast made that evening in Sandy's honor. She would have

enjoyed being a part of something so fun, so it was indeed a fitting tribute. SPOHNC will miss this dear lady, and will hold her in our hearts, with fond memories of her compassion for others, and her spirit and enthusiasm for all that she did for those she loved and cared for.

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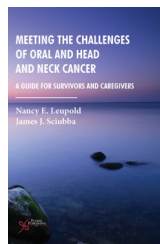


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